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ABSTRACT

A hearing was convened to investigate health care issues affecting children. Witnesses provided information about the way in which the health care system meets the needs of children in the United States. Components of the system include Medicaid for low-income children, the Maternal and Child Health block grant program, employer-sponsored health insurance, and Medicare for a small number of children with end-stage kidney disease. Testimony concerned Medicaid's adequacy, enrollment barriers, needed improvements, and recommended expansions; private insurance and insurers' case management procedures for children with severe and chronic health problems; prenatal care; the need for legislation to decrease infant mortality and expand coverage to poor, uninsured infants and pregnant women; health care policy and programs in several states; prevalence of chronic illness; use of health care by disabled children; paying for health care costs; Blue Cross and Blue Shield coverage and benefits; policy and program directives to specialized populations needing health care; the cost-effectiveness of expanded access to prenatal care for poor women; improved access to primary care and effective well-child care for young children; problems in financing and delivering health services for technology-dependent children; and child health activities of the Department of Health and Human Services, the Indian Health Service, and the Alcohol, Drug Abuse and Mental Health Administration. An extensive Congressional Research Service report on federal programs and policies on health care for children is included. (RH)

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CHILDREN'S HEALTH CARE ISSUES

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HEARING

BEFORE THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

MARCH 23, 1988

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CHILDREN'S HEALTH CARE ISSUES

WEDNESDAY, MARCH 23, 1988

U.S. SENATE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 10:06 a.m., in room SD-215, Dirksen Senate Office Building, the Honorable Lloyd Bentsen (chairman) presiding.

Present: Senators Bentsen, Baucus, Mitchell, Rockefeller, Daschle, Danforth, Chafee, Heinz, Wallop, and Durenberger.

[The prepared statements of Senators Danforth and Chafee appear in the appendix.]

[The press release announcing the hearing follows:]

BENTSEN ANNOUNCES FINANCE COMMITTEE HEARING ON CHILDREN'S HEALTH CARE ISSUES

WASHINGTON, D.C.—Senator Lloyd Bentsen (D.-Texas), Chairman, announced Thursday that the Senate Finance Committee will hold a series of hearings to review current programs and policies relating to children's health care.

The first hearing is scheduled for Wednesday, March 23, 1988 at 10:00 a.m. in Room SD-215 of the Dirksen Senate Office Building.

Bentsen said, "Last fall, I made a commitment to place the health needs of America's children at the top of the agenda for the Committee on Finance in 1988. This country can no longer afford to close its eyes to the toll taken by inadequate access to health care for our children who, although they do not vote and have little political influence, represent our destiny.

"This hearing is the first in a series which will focus on children's health care issues, including the problem of infant mortality and the financial burdens on families when a child is struck with a costly, chronic illness. I look forward to hearing from experts in government, academia and the private sector about the complex challenges we face in children's health care," Bentsen said.

OPENING STATEMENT OF HON. LLOYD BENTSEN, A U.S. SENATOR FROM THE STATE OF TEXAS, CHAIRMAN, SENATE FINANCE COMMITTEE

The CHAIRMAN. Please cease conversation and take your seats, and this hearing will be under way.

Last fall, in proposing the legislation to create a National Commission on Children, I indicated that we wanted to make 1988 the year of the child during which we dealt with child issues—health issues in particular—and that those in use would be a priority for this committee.

Now, this morning we are going to hold the first in a series of hearings on health care issues that affect children. I find few issues that have provoked as much interest among the members of this committee as this one. Before these hearings are completed, you will see that virtually every member of this committee will have been in attendance.

Already this year I noticed that we have had a great many bills relating to infant mortality introduced, with Senators Bradley and Durenberger and many other members of this committee as sponsors or cosponsors.

The health problems facing our children are complicated and they are multifaceted, and we cannot as a nation continue to neglect them. One thing we want to encourage, to the best of our ability, is that we have children born with healthy bodies and sound minds.

The United States today ranks seventeenth among the developed countries of the world in its infant mortality rate, and that is a disgrace. We have made no progress in that area at all since 1985. A white infant born in this country is two-thirds more likely to die in his first year than a baby born in Japan. A Black baby born here in Washington, or in many other of our nation's cities, is more likely to die before its first birthday than a baby born in Jamaica.

The Guttmacher Institute recently reported that as many as 35 percent of American pregnant women get less than sufficient prenatal care, and that, despite evidence that investments in prenatal care are returned three dollars for every one dollar that we invest during that first year of an infant's life.

Health care costs can become an issue even for families with incomes well above the poverty line. One in five American children have no public or private health insurance. Of 37 million uninsured Americans, 12 million are children, nine million of whom are dependents of workers who lack insurance against any health care costs.

Finally, every American family faces the specter of a high-cost catastrophic illness, sometimes of a chronic nature. The parents of a catastrophically ill child suffer not only the untold emotional stress that goes along with it, but they can see their life savings wiped out by the incredible costs that are involved in caring for that child.

I had a meeting in Houston the other day with representatives of the children's hospitals there, and they told me that the first child born this year in Houston cost over $25,000. Now, how does the average family with ordinary financial means handle a situation like that?

Some of these needs are not met by even the most comprehensive of health plans. I know that the number of affected children is small, and that may cause some to believe it is not a serious problem, unless it happens to your child or your grandchild. The cost for an individual family can be absolutely devastating.

Nationally, we have an estimated 19,000 children that incur health care costs in excess of $50,000 a year.

Today, we are going to hear from witnesses from Government and the private sector about the way in which the current patchwork health care system meets the needs or doesn't meet the needs of American children. That system has many components: Medicaid, for low-income children; maternal and child health care block grant programs; employer-sponsored health insurance that covers the majority of the nation's children; and Medicare for a small number of children with end-stage kidney disease.

Now, of course, I know there are some success stories to be told; but on the other hand, we have much further to go before we can be certain we have done what is reasonably possible to assure that all children have access to adequate and affordable health care. Failure to grapple with the problems faced by children and their families will shortchange this country of the strong and healthy leaders that we need in the next generation.

It is not an exaggeration to say that America's children are our future. We can choose to invest in them, or we can close our eyes to the problem of inadequate health care coverage for children. There is no one who is more aware than I of the difficulty of improving child health programs in a time of budget constraints; but we should not be deterred from a goal that both compassion and cost effectiveness tell us has to be met.

I am confident that this committee is dedicated to that effort.

Looking out there at that audience, I used to be on the Board of Directors of the Texas Children's Hospital; and I know that we have quite a number of members of Texas Children's and other hospitals in Texas. And they have presented me with a spring blue bonnet—it is a yellow rose—so that is the reason for my wearing it this morning.

I want to welcome Governor Mabus who has really taken a lead on these issues, first as a State auditor and now as a governor. He has played a very major role in a much improved Medicaid Program in his State.

I would like to defer to any of my colleagues who might want to make a statement. Senator Rockefeller?

OPENING STATEMENT OF HON. JOHN D. ROCKEFELLER IV, A U.S. SENATOR FROM THE STATE OF WEST VIRGINIA

Senator ROCKEFELLER. Mr. Chairman, number one, I am really glad that you have initiated this effort—a series of hearings on children's health care. Number two, I think it is terrific to look out in the audience and see a full audience.

When we discuss tax problems, people line up outside in the halls. Too many times, in the past when we have discussed children's problems, there hasn't been more than a handful of people here. That is changing, and that is appreciated because this is not a very cheerful subject.

Out of the 20 most industrialized countries in the world, we rank nineteenth in terms of infant mortality. I don't know quite how one even begins to explain that, particularly when we ranked sixth back in the 1950s.

We have been doing badly. The rate of infant deaths in America and the efforts to reduce that have stagnated. I know when I was Governor of West Virginia, we put a lot of effort into trying to reduce infant mortality. That has now come to a stop, which is a shame.

Only about half of poor pregnant women in West Virginia receive medical care and attention during their pregnancies. The reasons are not mysterious. I think we are going to have to confront the fact that the way to overcome many of these problems is money.

And that is tough in a year like this or in any year. But neglecting children is immoral on our part; and I believe it is your purpose, Mr. Chairman, to see that we do not, and you are right. Thank you.

The **Chairman**. Thank you very much, Senator. Are there any other comments?

Senator **Mitchell**. Mr. Chairman, if I may?

The **Chairman**. Senator Mitchell?

OPENING STATEMENT OF HON. GEORGE J. MITCHELL, A U.S. SENATOR FROM THE STATE OF MAINE

Senator **Mitchell**. First, Mr. Chairman, I commend you for this hearing and the action which I hope and am confident will follow as a result of this hearing in your efforts.

Our children are our joy; they are our future leaders scientists, teachers; but too many of our children are now at risk. Too many lack the services we consider basic to all citizens in our society.

They are subjected to more poverty and less health care coverage than at any time in our recent history. These problems have created a terrible disparity in America today. Our wealth as a nation continues to increase, but many of our children and their families are worse off.

One out of five American children has no health insurance. Many others have only partial coverage. When these children need primary care or major hospitalization, something has to give. All too often, it is the health of the child.

Families must delay necessary services or face bills that are simply overwhelming. A solution must be found. It will require the participation of all in our society. We in the Congress can craft helpful legislation. We can try to apply some of the limited resources of the Federal Government to deal with some aspects of this problem. But it will take the efforts of all Americans—mothers, fathers, churches, private agencies, local and State government—all must join in the effort.

Real improvements in health will require nurturing, organization, and the commitment of resources. The next generation must have the same opportunities available as the current and past generations.

We ought to bear in mind as we consider this problem the words of Pablo Cassals, who once said: "We must all work to make this world worthy of its children." Thank you, Mr. Chairman.

The **Chairman**. Thank you, Senator Mitchell. Senator Baucus?

Senator **Baucus**. Mr. Chairman, I am very happy you are having this hearing today. I want to make two points. Number one, the effort here is in the nature of prevention. Certainly a lot of child care is remedial, but these are children, after all; and therefore, there is a very strong prevention component in what we are trying to undertake here, which pays terrific dividends on down the road and in the future.

I think too often in America we spend too much time on remedial care and not near enough time on prevention, and this is in the nature of prevention, I think, and is an effort we should pursue even more fully.

The second point. Many children suffer or are beginning to suffer poor obstetrics; that is, many doctors, particularly in rural areas—because of the high cost of medical malpractice—are no longer delivering children. That is particularly a problem in rural areas.

In fact, in my State of Montana, one-half of the doctors—the OB-GYNs or family practitioners—by the end of next year will probably no longer deliver children because the medical malpractice premiums are so high.

In addition, in Montana one out of four deliveries are reimbursed by Medicaid—in my State of Montana—one out of four. In the State of Montana, physicians receive about 40 to 60 percent of the normal reasonable charges, which obviously is insufficient to cover their costs.

So, the degree to which Medicaid begins to help pay a larger portion of delivery costs will then be able to begin to solve the medical malpractice problem and the flight of physicians—whether OB-GYNs or family practitioners—from rural areas and also some urban areas in our country in delivering children.

So, there are lots of components to this. And certainly, the degree to which Medicaid can be part of the solution, thereby increasing the Medicaid payments to OB-GYNs and to other practitioners, that will help solve that problem as well.

So, I commend you, Mr. Chairman, for conducting this hearing.

The Chairman. Thank you, Senator. In the order of arrival, next was Senator Durenberger.

OPENING STATEMENT OF HON. DAVID DURENBERGER, A U.S. SENATOR FROM THE STATE OF MINNESOTA

Senator Durenberger. Mr. Chairman, thank you for the opportunity to do what we are doing today, and thanks for identifying your boutonniere. I have been a trustee of the Minneapolis Children's Health Center for something like 20 years; they forgot the flowers. I guess it isn't spring in Minnesota yet. [Laughter.]

But it is just great to be with you on this issue. It is something that I have enjoyed about you all of the time that I have been a member of this committee, which is 10 years now. When it seems like a struggle and we listen to all the statistics, it is as though nobody cares, but for all of the really big important things we throw around here—international trade, taxes, and all that sort of thing—when you get down to it, Lloyd Bentsen's heart is with kids.

And that is why I know it has to be a frustration for a lot of us on this committee, to have to deal with deficits and all that sort of thing, while we are also trying to deal with some of these realities.

Last year, Bill Bradley and I introduced the bill that would allow the States to enroll pregnant women and children in Medicaid up to 185 percent of the poverty level, which passed; and we hope that has some small impact.

But now, I guess we are moving into the more comprehensive phase; and I know Bill has a bill, and I have one, and there are various approaches that I trust this committee will be able to give its attention to during the course of this year and into the next.

I think it is appropriate while we are all facing up to doing catastrophic and being condemned for not doing enough in catastrophic health insurance for the elderly, and being told by some senior House members that we have got to take away our children's investment in their parents' retirement in order to expand those opportunities even further, that somehow or other we don't find it in our hearts or our pocketbooks to find the relatively small amount of dollars that the States are willing to help us match to deal with the consequences of the disintegration of the family and widespread permissiveness and overindulgence and the dependence on drugs and alcohol and tobacco and unwanted pregnancies and maternal deaths and sexual abuse and prostitution and psychological disorders and suicides and violence and death and all those sorts of things that are afflicting the family in America today.

These are at least as serious as long-term care for elderly and disabled Americans, and I trust that on this committee they are going to get at least equivalent attention, Mr. Chairman.

The CHAIRMAN. Thank you, Senator. Senator Chafee?

OPENING STATEMENT OF HON. JOHN H. CHAFEE, A U.S. SENATOR FROM THE STATE OF RHODE ISLAND

Senator CHAFEE. Mr. Chairman, I would like to join in the tribute to you. You have had a long-time interest in children, and this is but one further evidence of that. I want to just say how glad I am that we are proceeding with these hearings.

It is an area that I have been interested in for a long time. I would like to say that we have made some progress, and progress can be made.

If you look at the record, in 1984, in the Deficit Reduction Act, we were able to include a small expansion of Medicaid to provide voluntary coverage to children up to the age of five in families with low incomes. And then in 1985, we were able to extend prenatal coverage to all pregnant women who were beneath the State income standards.

Then in 1986, we included a provision to allow States to cover children up to the age of five and pregnant women up to the Federal poverty level, even if these individuals were not eligible for the State AFDC Program. I think that is very important that we continue, and that the individuals not be required to be eligible for another support program in order to get the Medicaid assistance.

Last year in 1987, we were successful in including a provision in the reconciliation agreement which would allow the States to extend Medicaid coverage to pregnant women and children up to the age of one for those who are below 185 percent of the poverty level and to all poor children up to the age of eight. This is what Senator Durenberger was describing.

As Senator Baucus mentioned, and I would like to reinforce this, we have got a situation in the United States where we are wonderful at treatment of low birth weight babies; there is no question about it. No one excels the United States in treating low birth weight babies, but we don't have a very good prevention program.

Thus, as has been mentioned, our rate of low birth weight babies is higher than other countries. And there is no more cost-effective way, I believe, in providing preventive medicine than in the proper prenatal care.

The Academy of Sciences estimates a cost/benefit ratio of about $3.50 saved in the first year of a child's life for a dollar spent in proper prenatal care. So, just looking at the finances, it makes sense. Never mind the heartache and the wrenches that come in having a child who is born prematurely at low birth weight and all the difficulties that come with that.

I hope in the course of this we will be able to take a look at a program I have been most interested in that I have presented, called MedAmerica, which is S. 1139, which would build on the Medicaid Program in various ways.

I would like to submit a statement, if I might, going into more detail on that.

The CHAIRMAN. Yes, of course, Senator. And those things you talked about in 1984 and 1985 and again in that budget summit reconciliation bill, the members of this committee took the lead on that.

Senator CHAFEE. I think we have good reason to be proud of that, Mr. Chairman.

The CHAIRMAN. Yes. Governor Mabus, we are very pleased to have you. If you would proceed with your testimony?

STATEMENT OF HON. RAY MABUS, GOVERNOR, STATE OF MISSISSIPPI, TESTIFYING ON BEHALF OF THE NATIONAL GOVERNORS ASSOCIATION

Governor MABUS. Thank you, Mr. Chairman, and thank you, members of the committee. As the chairman said, my name is Ray Mabus. For the last 2 months, it has been my great good fortune to be the Governor of the State of Mississippi.

I appreciate the opportunity to testify on behalf of the National Governors Association as to the actions that States have taken with a lot of help from the Federal Government to address the problem of infant mortality. I am not going to go into a lot of statistics on infant mortality this morning; you have got experts that can and will testify to those.

But I do have one expert of my own sitting in the audience, and that is Jeanne Luckett, the Chairperson of the Governors Task Force on Infant Mortality in Mississippi, one of the real heroes in this effort.

If I could make one point this morning it would be this. Each statistic in infant mortality represents human tragedy and heartache, lives unfulfilled, and future leaders lost; and each statistic in low birth weight babies means too many of our citizens will go through life mentally retarded, robbed of the opportunity to get the most out of their lives.

Despite a lot of progress, our nation continues to be plagued by unacceptably high infant mortality rates. The problem has been particularly acute in the South. In 1985, the national average was 10.6 deaths per 1,000 live births, while in the South it was 12.4.

During my entire public life, education has been my number one priority; but I have come to realize that there is more to education than simply teaching in the classroom. Our ability to educate and to be educated depends on the health of our brain cells, which develop in the first three months after fertilization.

When we fail to reach those among us who are the most vulnerable, particularly the poor and the non-White, we lock ourselves into a perpetual cycle. As Senator Chafee said, there are two basic reasons we should fight to lower the infant mortality rate in this country and the low birth weight rate.

First, we should do it because it is right and good and the decent thing to do; but the second reason is purely selfish. It costs us more to let the tragedy continue than it does to prevent it. If the cost in human terms is not alarming enough, the economics are staggering.

In Mississippi alone it was estimated that infant deaths and handicapped infants born in 1985 resulted in the loss of about $55 million in projected lifetime earnings and cost the State $3.2 million in potential revenue from personal taxes. This doesn't count the money spent on care for babies born with preventable handicaps, who live to adulthood. However, we are all aware that the problem is not unique to Mississippi or even to the South. It is a truly national problem in scope; but because of the magnitude of the problem in the southern States, former Governor Richard Riley of South Carolina and other governors in 1984 established the Southern Regional Task Force on Infant Mortality.

I think that Dick Riley deserves a lot of praise for bringing this to the attention not only of southern governors but also of the nation. The most significant and far-reaching task force proposal that Governor Riley called for was revising the Medicaid Program to allow children and pregnant women whose income was at or below the Federal poverty line to receive Medicaid services.

The National Governors' Association adopted this as its policy in 1986. This was the first time that the NGA embraced the idea that eligibility for Medicaid should be based on the income and assets of the individual and not on other categorical requirements related to cash assistance programs.

Rules and regulations which properly apply to direct cash payments should not frustrate a person's access to health care. The governors feel strongly that endangered women and children should face far fewer barriers to decent medical care.

Separating the Medicaid Program from the cash assistance program made good economic sense. It allowed States to get the most for their money. Each dollar spent on prenatal and infant care saves many future dollars.

Because of this committee's leadership, the Omnibus Reconciliation Act of 1986 included those proposals by the NGA; and the 1987 OBRA allows States to extend coverage to children up to age five with income at or below the Federal poverty level. It also provides optional coverage to pregnant women and infants with income at or below 185 percent of that poverty level.

In the South, the response has been dramatic. Of 17 southern States, and the District of Columbia, 16 have taken advantage of providing coverage to pregnant women and infants. The other two are considering this proposal.

I am proud to say that nearly all the States in my region have adopted aggressive policies to fight infant mortality. Even so, infant mortality continues to have a crippling effect on my State and on States throughout this country; and we in Mississippi are engaged in an all-out battle to defeat it.

In 1976, Mississippi's infant mortality rate was 42 percent higher than the national average, and we were solidly in last place. We remained there until 1985, when Mississippi moved from fiftieth in the country until today we are forty-seventh; and the infant mortality rate has plummetted from 21.6 deaths per 1,000 live births in 1976 to 12.3 in 1986. We have moved ahead by making the best possible use of the Medicaid Program.

First, we expanded our Medicaid Program to include the married poor, long before it became a Federal mandate to do so. Under the OBRA 1986 option, we were among the first States in the Nation to move eligibility standards to 100 percent of poverty.

These combined efforts are expected to provide coverage for at least 7,000 more pregnant women and 46,000 more infants when fully implemented.

In addition to Medicaid expansion, we have instituted other creative means of stretching our limited resources. More than 40 percent of the pregnant women in the State, or approximately 17,000, are served by public health departments which receive $7 million under the MCH block grant. About 60 percent of all children born in Mississippi benefit from the WIC Program, the highest service rate in the region.

Mississippi, with Federal assistance, provides family planning services to 100,000 women in the State, one-third of whom are 20 years old or younger. And using Federal help, Mississippi has hired a paranatal nurse and used existing State-operated hotlines to help women having problems gaining access to medical care. These calls are reviewed every two weeks and serve as a basis for changes to close gaps in the system.

Mississippians are justifiably proud of our State's improvement in infant mortality, but we can't afford to relax. Nearly a quarter of the Mississippi women who gave birth in 1986 received no care until after the first trimester of pregnancy. Furthermore, the infant mortality rate for non-Whites remains shocking and unacceptably high, almost twice the rate for Whites; and the percentage of births which are low weight babies remains relatively unchanged.

The lesson we have learned in Mississippi is one that applies to this Nation. We pay an exorbitant price when we fail to provide our people with the tools they need to become productive citizens. Being born healthy is the most basic tool of all.

In these days of limited Federal resources, investment in the problems of infant mortality is an investment in our future. The programs I described to you are cost effective and they work. For every dollar invested in combatting infant mortality, States save up to $10.00 in future expenditures.

The National Governors' Association believes strongly that Congress should continue to use Medicaid to decrease infant mortality and improve the health of all low income and disadvantaged children. We continue to support this committee's efforts to make Medicaid funds available and to grant States the flexibility to tailor Medicaid programs to their specific needs.

Mr. Chairman, thank you for this opportunity and thank you for holding these hearings.

The **CHAIRMAN**. Governor, we are pleased to have you here, and I want to congratulate you and a number of other governors who are taking very aggressive steps to try to face up to this infant mortality problem and to improve Medicaid coverage. I hope that this year we can do some things to be of assistance from the Federal standpoint in helping you do the job that has to be done on Medicaid coverage.

But apart from that, I also understand that it is not just a question of increasing the coverage. One of the problems is getting some of the providers to participate in the Medicaid health delivery system. There is some concern about the cost and what is paid for the different services. Would you comment on that?

Governor **MABUS**. We have had some success in Mississippi in attracting more providers into the system by raising the rates to a more competitive level. They are still not the rates that you would get for treating private patients, but we are having success, particularly in getting pediatricians in. As several of the Senators mentioned—Senator Baucus in particular—there is a problem with medical malpractice rates, particularly in rural areas of States like Montana and Mississippi; and that is something we are not having much success with.

But as we have begun to raise the rates for OB-GYN and family practitioners, they have begun to get back into the Medicaid system and are providing much more care now for pregnant women and infants.

The other thing that we have done is to regionalize our perinatal care and to do a triage system, which is to identify and closely track the higher risk women so that we can move them into tertiary care centers as quickly as possible.

The **CHAIRMAN**. What do you think we can do together to try to improve the system, to reach the objectives that we both share?

Governor **MABUS**. I guess the simple answer from a State point of view is money.

I think that doing things like raising the limit over the Federal poverty limit to 185 percent is certainly a step in the right direction. It may be that you will want to look at even removing any limits on Medicaid for pregnant women and very small infants.

I know that Mississippi, even in the midst of very tough economic conditions, moved to 100 percent of poverty when the Congress allowed us to. The Mississippi House has already passed a bill allowing us to move to 185 percent. The Senate is taking it up now.

So, I think that those sorts of programs help—allowing more flexibility, allowing more coverage, and continuing to decouple Medicaid from other programs. We simply couldn't afford to put Medicaid in, if people who were automatically eligible for Medicaid became eligible for AFDC, for example. But we can afford to participate in the Medicaid Program.

The **CHAIRMAN**. Thank you very much. Because of the interest of other members, I will yield the balance of my time. Senator Rockefeller, you are first on the list of arrivals.

Senator **ROCKEFELLER**. Thank you, Mr. Chairman. Governor, let me just say that you may have been governor for only two months, but you sound like you are a real veteran and what you have said is very valuable.

West Virginia and Mississippi usually share similar statistics in problems such as infant mortality, so I especially respect what you are doing. In West Virginia, a doctor reimbursed by Medicaid for care provided to a poor pregnant woman is going to receive less than he would otherwise charge. In fact, OB-GYNs often lose money—in some cases, the cost of malpractice insurance to see the woman is greater than what the doctor receives from Medicaid for that patient.

So, doctors almost cannot afford to see poor women. Senator Baucus was referring to this problem—the cost of medical malpractice insurance—and the trend of doctors dropping out of Medicaid. This situation is certainly true in your State, and it certainly is true in my State. Another problem is that States regulate insurance; the Federal Government used to, but doesn't any longer.

What are States doing about this; is there any role which you think the Federal Government or the Congress might play which would be helpful?

Governor **Mabus**. In terms of insurance, my State—as I know many others—has looked at what has been termed Tort Reform. We have not passed very few of those bills; and in fact, most were very unsuccessful in this session of the Mississippi legislature.

One of the reasons is just what you said; States regulate insurance, and the Federal Government does not. A State the size of Mississippi or West Virginia doesn't have much leverage against an insurance company that says we will just quit writing coverage if you begin to regulate us very closely.

In terms of getting doctors back into the system, 2 years ago we paid $8 per visit for a pregnant woman for any procedure. Understandably, doctors were reluctant to provide care. We have raised those rates pretty dramatically. They are still not quite competitive with the private sector, but they are getting fairly close; and we are beginning to see that doctors are willing, not solely out of economics, but out of a sense of responsibility, to move back into the system.

We are still losing far too many because of the malpractice rates, particularly as Senator Baucus said in the rural areas.

In a Jackson, Biloxi, or a Tupelo area, we are not having very serious problems; but in my home county of Choctaw which has 8,000 people in the whole county, or other rural counties it may be very hard to find somebody to do a delivery.

One of our responses has been to try to get family practitioners to identify high-risk women and then pass them along to our health system and to our State hospitals, particularly the University Hospital, for care so that the high-risk babies can receive that intensive care that they need without exposing doctors to that malpractice risk.

Senator **Rockefeller**. Thank you, Governor.

The **Chairman**. Senator Mitchell?

Senator **Mitchell**. Thank you, Mr. Chairman. Governor, I commend you for your statement, for your interest in this area. Many of us have observed and followed you from afar with interest and admiration, and we are very grateful and hopeful for what you are doing in your State and are pleased to have the opportunity to hear you and work with you.

You are here, of course, on behalf of the National Governors' Association; and one of the most difficult areas that we confront in our relationship with the governors and local units of government is mandates, the difficulties that follow particularly with mandates that are unaccompanied by adequate funding.

Now, in the particular area that we are dealing with, there are a number of pending bills in the Senate now to mandate States to increase Medicaid coverage for maternal care for women and families with incomes up to the poverty level. Obviously, this is something that you share in terms of the objective.

My question is: As a Governor yourself and as a representative of the National Governors' Association, what is your reaction to that?

Governor **Mabus**. I will give you two answers.

Senator **Mitchell**. All right.

Governor **Mabus**. I will give you one as the Governor of Mississippi, and I will give you one as a representative of the NGA.

As a representative of the NGA, the NGA has not taken a position on mandating that sort of coverage. And as a general rule, the NGA likes to have options instead of mandates directed toward the States.

As a Governor of a State that has already moved to 100 percent and the fact that 33 other States have moved to that, it would only have a positive impact on Mississippi. And I say that because, in times of budget crisis, Medicaid is one of the first things to look at to cut, and if there is a mandate there, it would prevent us from reaching some of those dollars that should not be reached.

So, as the Governor of Mississippi, I would think that there are some benefits.

Senator **Mitchell**. You said there are 33 States now that have moved voluntarily to that level?

Governor **Mabus**. That is my understanding, 33 States counting the District of Columbia.

Senator **Mitchell**. And I gather that is continuing to move in that direction? An increasing number of States are doing that?

Governor **Mabus**. In the South, 16 of 18 have moved; and the other two have not because of budgetary constraints, but both have considered making the move. And I think as soon as their budget crises ease up a little bit, they will also make the move. The economics are just too good, the savings are too great, not to do so.

Senator **Mitchell**. One of the most difficult areas to deal with in this whole subject is reaching the working poor. This is one way to do it. Do you have any other thoughts that you could either offer us now or submit later in writing, if you choose to do so?

Governor **Mabus**. One of the things that we have been trying to do, since we have a good system of public health clinics in Mississippi, and we have been trying to move more of our dollars into prevention instead of waiting until acute care, trying to catch high-risk—particularly infants, pregnant women, and the elderly—persons before they become real problem cases.

Senator **Mitchell**. I would just conclude by saying that your words on prevention echo in this room because Senator Bentsen and Senator Chafee have been leaders in educating this committee and the public in that regard and have taken the lead in urging a redirection of our priorities. And I think that is something that we must increasingly do as a Government and as a society. Thank you very much, Governor. I really appreciate your testimony, and we look forward to working with you and the other governors.

Governor **MABUS**. Thank you, Senator.

The **CHAIRMAN**. Thank you, Senator Mitchell. Senator Baucus is next. Let me say to my colleagues that, with all the intense interest we have here on this subject, we have five more panels of very interesting witnesses and authorities in their fields. Please keep that in mind as we try to move along. Senator Baucus?

Senator **BAUCUS**. Thank you, Mr. Chairman. Governor, Senator Mitchell mentioned how much he and others admire the work you have done; and I want to echo that. Mississippi is a State somewhat similar to Montana, somewhat sparsely populated in some areas. It is not one of the more wealthy States in the nation.

There is another tie actually; I think one of America's best contemporary writers today, Richard Ford, is from Mississippi. He also resides in Montana. In fact, he is in town this week, and there is an award to be given to him.

The question I want to ask you is this: What message would you give to governors of those States which have not boosted their prenatal care programs because of the need to balance the budget and cost constraints? You have gone a long way, and I want to give you a chance to very succinctly hit the bull's-eye and explain to these other governors and some other State legislators why they should spend those prenatal dollars up front and why it is in their economic best interests?

What is the most compelling case you could make?

Governor **MABUS**. The most compelling case I could make is that if Mississippi does it, you had better do it. If we can afford to do it, any State can afford to do it because we are dead, solid last in too many of our economic indicators; but this is one of the ways we see of moving up on that list.

It is simply a question of where you want to spend your money. Do you want to spend a little early in prevention, or do you want to spend a whole lot later for handicaps that were preventable?

Senator **BAUCUS**. You are saying if Mississippi can do it, any other State can do it, too?

Governor **MABUS**. Yes.

Senator **BAUCUS**. Thank you.

The **CHAIRMAN**. Thank you very much, Senator. Senator Chafee?

Senator **CHAFEE**. Thank you, Mr. Chairman. Governor, you are certainly out of the blocks fast as a governor who has been in the chair for only two months. It is obvious that you grasp hold of things quickly and well.

I would like to ask you a quick question, if I might? We have encountered in our State the exact same problem that you have encountered regarding obstetricians and that Senator Baucus has. And indeed, we are reduced to the situation where we have scouts going across the country and reporting back that they have landed an obstetrician in San Francisco, and they drew number one in the draft rating for her; and she will be coming on soon.

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I believe a major factor in this involves not only the high rates for the liability insurance, but the hassle that comes with their being sued. People just don't want to be sued even though they may well be proven to be innocent or not liable when the verdict comes down.

Have you given any thought to a program where you would put limits on liability solely for obstetricians? I mean, if you tackle the whole thing, you have all the trial lawyers down your back; and you may well get them on your back if you try it even just with obstetricians. Have you given any thought to that?

Governor **Mabus**. We had looked at Virginia's program, which they passed, which was to take birth and problems associated with birth out of the Tort System and put it more into a workmen's comp/no-fault system.

That has been thrown out by a Federal court in Virginia, and we are awaiting the outcome of that.

Senator **Chafee**. We have exactly the same situation, where we just cannot provide proper prenatal care with all the good intentions and indeed proper funding; we haven't got the doctors.

Governor **Mabus**. I think there are some answers out there. As I said, we are waiting to see what problems the courts are having with the Virginia plan so that we can look at a plan that would meet those objections and be fair to all concerned.

Senator **Chafee**. Thank you, Governor. Thank you, Mr. Chairman.

The **Chairman**. Thank you. Senator Daschle?

Senator **Daschle**. No questions, Mr. Chairman.

The **Chairman**. Senator Wallop?

Senator **Wallop**. No questions, Mr. Chairman.

The **Chairman**. Governor, thank you very much. That will be a great deal of help to us.

Governor **Mabus**. Senator, thank you on behalf of Mississippi and the NGA.

[The prepared statement of Governor Mabus appears in the appendix.]

The **Chairman**. Our next panel will be Dr. William Roper, Administrator of the Health Care Financing Administration, Washington, DC, and Dr. Robert Windom, Assistant Secretary for Health, Public Health Service, Department of Health and Human Services, Washington, DC. Gentlemen, we are pleased to have you. Dr. Roper, if you would proceed with any prepared testimony you have?

STATEMENT OF WILLIAM L. ROPER, M.D., ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION, WASHINGTON, DC

Dr. **Roper**. Thank you, Mr. Chairman.

The **Chairman**. We will have to operate under a time limitation of five minutes, and we will take your entire statement for the record; and then we will open it up for questions.

Dr. **Roper**. Thank you, sir. I will be brief. I have had the privilege in my two years as HCFA Administrator to testify many times before this and other committees. Never have I had an occasion to testify about something I feel as strongly about as I do this subject today.

I am a pediatrician; my wife is a pediatrician, and we care deeply about the health of children, and I commend you for having this hearing today on this very important subject. I wore my bow tie today because I am proudly a pediatrician. [Laughter.]

I commend you, to begin with, as chairman for your efforts with establishing the National Commission on Children and the activities of that commission. I know other members of the committee have put forward legislation dealing with the issues of children's health.

As Administrator of the Health Care Financing Administration, I have responsibility for Medicare and Medicaid, and we pay for the health care services of 11 million children in our nation. The Medicaid Program is the primary source of health care for the most vulnerable of our children, those who are poor and disabled.

I am pleased to report to you this morning that the Medicaid Program is serving the needs of its recipients in essential and innovative ways. For a good part of its history, the Medicaid Program was linked to the receipt of welfare benefits, but recent Congressional action has removed that link for some groups of recipients.

States now have the option, as Governor Mabus was telling you, of providing Medicaid coverage for pregnant women and certain children who are not AFDC eligible because their income exceeds the State standards. Since Medicaid is a State-operated program, the real story is how the States, in facing new diseases, complex care needs and fiscal problems, are meeting the challenge of caring for low income children.

Increasingly at the State level, State Medicaid agencies, maternal and child health agencies, with the WIC Programs, local and State health departments and others are sharing resources and personnel to meet the health care needs of children.

Before I came to work in the Federal Government, I was county health officer for the six counties around Birmingham, Alabama, and have direct, personal experience in this area. Agencies' programs working together can solve the problem of infant mortality and the other health care issues facing our children. We in the Health Care Financing Administration are encouraging States to increase their cooperative efforts.

For example, we have formed a Maternal and Child Health Technical Assistance Group, bringing together resources from the public health sector and the Medicaid sector to solve these problems together.

Today, more than ever before, we realize that a good start in life requires good prenatal care. Poor prenatal care and prenatal care begun too late in the pregnancy have been correlated with low birth weight babies and a number of other problems that follow from that.

States have made major progress toward improved access to prenatal care by streamlining the Medicaid application process and expanding coverage of women in poverty. Twenty States are covering pregnant women up to 100 percent of the Federal poverty line. Another 23 States are considering this option.

One of those 23 is my home State of Alabama. I was down at the governor's invitation; Governor Guy Hunt held a symposium in January on the question of infant mortality; and I urged the legislators to pass the governor's proposal to bring Alabama in line with the other States who have taken the important step of adding coverage for pregnant women up to 100 percent of the poverty line. I am hopeful that my home State legislature will do this important thing shortly.

Several States are considering the further option that OBRA 1987 gave to extend this coverage up to 185 percent of poverty. Also, they are considering giving quicker access to prenatal care through adoption of presumptive eligibility, also conferred by OBRA 1987.

All together, an estimated 650,000 additional low income women and children will be covered by Medicaid at the end of fiscal year 1989 as a result of these program changes. We also need to give credit to the important early and periodic screening, diagnosis and treatment program that provides well-child care and early intervention services to a large number of children who are in the AFDC Program.

We have recently issued a new Medicaid manual instruction to the States to help them do a better job of managing the EPSDT Program.

Another important responsibility of the Medicaid Program is serving some 300,000 children who are on the SSI Program. In 1981 and 1982 the Congress passed legislation authorizing waivers and a State plan option which would permit the States to pay for medical care administered to children in the home if home care is less expensive than institutional care.

Other activities of my agency dealing with children's health include the end-stage renal disease program; and I would be happy in the question period to talk about significant activities Secretary Bowen has launched in conjunction with the Public Health Service and HCFA dealing with the health of children.

This is an important subject, and I am pleased to be with you today.

The CHAIRMAN. We are very pleased to have you, Doctor. Your testimony is helpful. Dr. Windom, if you would proceed?

[The prepared statement of Dr. Roper appears in the appendix.]

[Questions from Chairman Bentsen and Senator Baucus to Dr. Roper follow:]

QUESTION FROM CHAIRMAN BENTSEN TO DR. WILLIAM ROPER

Question. Several of our witnesses today have submitted statements indicating that Medicaid enrollment procedures raise significant barriers to access to prenatal care for pregnant women. In the 1986 Reconciliation Act, Congress made possible a determination of "presumptive eligibility" for pregnant women to expedite their application to Medicaid. Has this approach been successful? What else could be done to improve access to prenatal care for Medicaid-eligible women?

Answer. Twelve States have adopted the presumptive eligibility coverage option. This option allows a pregnant woman who appears to meet Medicaid eligibility requirements to be covered from the moment she walks into an approved provider's office, seeking care. The State guarantees approved providers that it will cover those expenses even if the woman is determined ineligible after the formal Medicaid application process. Assuring that bills will be paid for initial visits reduces the woman's and the provider's uncertainty over payment and increases the likelihood that the woman will seek care and that the doctor will continue to provide care.

Some States have initiated other programs to simplify the Medicaid application process. Several State agencies have placed Medicaid eligibility workers at major hospitals, clinics, and large providers' offices to complete the Medicaid applications on site, when the woman comes in for care. Seventeen States have dropped the assets test for pregnant women. Eliminating this test considerably speeds up processing of the Medicaid application because investigating the assets statement is a lengthy process.

QUESTIONS FROM SENATOR BAUCUS TO DR. WILLIAM ROPER

Question. What is the average, the high, and the low Medicaid reimbursent amount for prenatal care, deliveries, and well baby care? How do these amounts compare with normal charge levels?

Answer. States are granted flexibility to develop their own payment rates. Some are increasing rates for prenatal care due to problems with access to obstreticians in some areas. HCFA does not maintain records on the various payment levels set by each State.

Question. You mentioned that Alabama has recently increased its Medcaid payment amounts for physician services. Please elaborate on the increases you referred to. How have these changes affected physician participation and the number of Medicaid eligible women and children served?

Answer. In January of 1988, the Alabama Medicaid program increased payments for vaginal deliveries from $450 to $675. Although actual increase in participating physicians has not been sustained, Alabama officials have noted fewer provider complaints since this increase.

Question. What efforts does your agency make to evaluate the adequacy of Medicaid provider payments? Do you believe that there is a federal responsibility to determine whether reimbursement levels for Medicaid are adequate to take any action to get States to address persistently low reimbursement levels?

Answer. Under the law States have been granted great latitude for rate setting. States may determine their rates based on a number of factors including reasonable cost, Mediciare upper limits, and the State's fiscal situation. We encourage States to set rates that facilitate adequate provider participation, but we do not evaluate their payment methodologies.

STATEMENT OF ROBERT E. WINDOM, M.D., ASSISTANT SECRETARY FOR HEALTH, PUBLIC HEALTH SERVICE, DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC, ACCOMPANIED BY VINCE L. HUTCHINS, M.D., DIRECTOR, MATERNAL AND CHILD HEALTH PROGRAMS, PUBLIC HEALTH SERVICE

Dr. **WINDOM**. Mr. Chairman and members of the committee, I also welcome the opportunity to appear today to discuss the common concern we have for the health of our nation's children. I am joined on my left by Dr. Vince Hutchins, who is Director of the Maternal and Child Health Program in the Public Health Service.

There are many challenges that face us in public health, but none is more important than assuring that our children are born healthy and able to grow and reach their full potential. We commend you, Mr. Chairman, for focusing the efforts of your committee this year on this crucial public health problem.

As a parent and as a physician, I am well aware of the consequences of health problems for children and their families. Our children's health status is a reflection of our own, and we have the responsibility to cure their ills and help them to achieve a healthy lifestyle.

This is a philosophy that I have encouraged at the Public Health Service also.

Seventy-five years ago infant mortality was the first issue that was studied by the Children's Bureau. Since that time, we have achieved substantial progress measured by a tenfold reduction in infant mortality.

However, the continued unacceptably high rate of infant mortality, especially among Blacks, and our concern that the rate of decline has slowed in recent years keep infant mortality as a major focus of our department.

When Secretary Bowen joined the Department of Health and Human Services, he stated that of all the areas of concern that he had, getting to the root causes of infant mortality was among the highest of his priorities. As an expansion of our many efforts currently under way, Secretary Bowen has added another initiative to reduce infant mortality through the community and migrant health centers that serve some of our most vulnerable population.

This effort will provide enhanced services through a case-managed comprehensive approach, focused on the coordination of appropriate services throughout pregnancy and the first year of life.

Let me also take a moment to mention a special task force on pediatric AIDS, which Secretary Bowen established last month. We are pleased that Dr. Bowen chose to lodge the primary responsibility for that task force in our Public Health Service. The chairman of the task force is Dr. Antonio Novella with the National Institute of Child Health and Human Development at the National Institutes of Health.

Nothing is more tragic than the plight of infants infected with AIDS. The goal of the task force is to ensure coordination of all departmental activities directed toward the care and treatment of these children, including research and demonstrations, and to determine the best use of our resources.

A representative from the Health Care Financing Administration sits on our task force.

On Child Health Day, October 1, 1987, the Public Health Service elevated the Maternal and Child Health Program from a division to the bureau level. This will enhance visibility of our program, provide the ability to better coordinate child health activities, and establish and focus within the Federal Government collaboration with other public agencies, professional and voluntary organizations.

Mr. Chairman, with your permission, I will provide a summary of our child health activities and submit my full statement of that for the record.

The **Chairman**. We will do that, Doctor.

[The prepared statement and summary of Dr. Windom appear in the appendix.]

Dr. **Windom**. Mr. Chairman, in the area of the maternal and child health program, as this committee is well aware, the Maternal and Child Health Block Grant Program, Title V of our Social Security Act, provides formula based allocations to States and insular areas for a broad range of health services, including preventive primary care and rehabilitative services to mothers and children.

We intend for the States to have a great deal of flexibility in the use of these funds. Of the $526 million appropriated under title V in fiscal year 1988, $444 million will go to the States in block grant programs. Fifteen percent of the title V programs are set aside for grants that are administered by the National MCH staff for special projects of regional and national significance, called SPRANS, in the areas of research, training, hemophilia, genetics, and other special projects.

We funded a total of 460 projects in fiscal year 1987 and will spend $78 million this year to support 490 projects. Nationwide, a primary emphasis on maternal and child health programs, which is responsible for a large measure of their success, is the integration of Federal, State, and private efforts. Such collaboration is indeed very important.

In the areas of child health research, we have many programs under way through the Institutes of Health and through other agencies. And just a sampling of that research is to better understand, treat and hopefully cure and prevent problems related to pediatric AIDS.

We have a multitude of other bits of information that we will provide for the record in that area.

In the Indian Health Service, we have very active child health activities that are showing measurable evidence of improvement. In our CDC child health activities, we have educational programs and surveillance, and information from that service is very much a part of our program.

I would like to mention that the CDC has contributed to child health by launching a comprehensive injury prevention and research initiative, including projects to identify causes, consequences, and remedies to prevent injuries to children.

The Alcohol, Drug Abuse and Mental Health Administration has many related activities such as of alcohol's effect upon the birth rate and the birth problems. And we will give that to you in further detail. We have a lot more to offer, Mr. Chairman, which we will provide for the record. I will be happy to answer any questions, if I am able.

The **Chairman**. Thank you very much, Doctor.

[The information appears in the appendix.]

The **Chairman**. I want to thank all of you gentlemen for your obvious commitment to the improvement of the health of children of this country. I was delighted to see in the President's budget an increase requested for maternal and child health care and am pleased with the signal that I think that sends.

Now, Dr. Roper, you are from a southern State; Alabama, did you say?

Dr. **Roper**. Yes, sir.

The **Chairman**. Which has had a relatively high infant mortality rate. As I understand it, before you came here you also held a public health position down there?

Dr. **Roper**. Yes, sir.

The **Chairman**. So, you had some exposure to providing health care to families with modest incomes—substantial exposure?

Dr. **Roper**. I was Director of the County Health Department in the urban county around Birmingham and then the five rural counties around that.

The **Chairman**. When we look at the problem of low income families, that is, health care for these infants and for the mothers, do you think at some point we should require from the Federal standpoint mandated coverage? Do you think that at some point a mandate is appropriate?

Dr. ROPER. I think the States need to do right by their citizens, and I am convinced that my home State is going to do what they ought to do and enhance the Medicaid Program. I believe that the Medicaid Program ought to be one where the States have substantial flexibility.

So, I continue to urge my home State, where I vote and pay taxes, to improve the program.

The CHAIRMAN. That is a very careful answer. [Laughter.]

You want them to have flexibility, but you want them to "get with it."

Dr. ROPER. They had better. I mentioned that I went down to Montgomery two months ago. Governor Hunt held a symposium on the question of infant mortality, and he has introduced a bill in the legislature to add the money that we will match $3 to the State's $1.00 to bring up to 100 percent of poverty the coverage for women and children.

And I said there—basically my answer to your question today—that I am a Federal official going around the country talking about the need for State flexibility; but if you, my home State citizens, don't do right by our fellow Alabamians, the people who believe in mandates are going to win this vote because there is just no excuse for a State even as poor as Alabama not to do this.

The CHAIRMAN. We have had some recommendations made to this committee that, when we get to the situation of special needs children—some of our older crippled children's services—that it might be helpful if some of the funds were redirected—the maternal and child health funds—to support services, leaving Medicaid as the payer of acute care medical costs.

What is your reaction to that kind of suggestion?

Dr. ROPER. Redirect which funds?

The CHAIRMAN. We are talking the maternal and child health funds for special needs children being redirected to support services, leaving Medicaid as the payer of acute care medical costs.

Dr. ROPER. Sure. That is something that ought to be looked at. I am not familiar with the proposal. It sounds like taking MCH money——

The CHAIRMAN. Dr. Windom, do you have some thoughts on that?

Dr. WINDOM. Dr. Hutchins may be able to answer that.

The CHAIRMAN. Dr. Hutchins?

Dr. HUTCHINS. As you know Senator, we have been looking for several years at how we can best put together programs for children with special health care needs. It is obvious that we have to cross various agency lines in order to do that. There are several issues involved.

One is direct medical care, which you asked about; much of that is currently being provided by Title 19 for those who are eligible. But those children also need other special services, which come from the other health disciplines which may not be paid for by either public or private third party insurers.

It also requires education and social services so that those agencies also have to be involved, and there has to be some way of putting that together.

I think, in responding to your question, the support services and the coordination of those services with the acute medical services is an appropriate role for Title 5 and is being carried out in some States to that effect.

The CHAIRMAN. In the interest of trying to save some time here, I will submit the rest of my questions in writing to you; and I would like answers on those.

[The questions appear in the appendix.]

The CHAIRMAN. Gentlemen, are there further questions?

Senator ROCKEFELLER. Thank you, Mr. Chairman. Dr. Roper, I respect very much your being here. I respect your professional training as well as that of your wife; but I must say that, whereas it is true that States have been making progress, and you reflect that in your statement, it does occur to me that the States cannot do it all.

The fact is that Medicaid only covers one-half of all poor children. I don't know how we tolerate that. To be honest with you, and I don't mean to be partisan on this, we have had a history—from 1981 through 1984 and then intermittently since then—of caps on Medicaid, cuts in the child care block grant, WIC, and food stamps, and a persistent pattern of undermining these program's through the submitted budgets of the Administration.

In your report here, I don't see suggestions for improvements. Under the department studies of improved health care, you say:

"We are proud of Medicaid's success. We recognize this is a continuing challenge," which I think is certainly a modest statement; but then you say:

"The department has established several working groups exploring policy, exploring program directives, examining problems." Nothing about producing specific actions to be taken by the other part of government called the Federal Government, in terms of reducing infant mortality and other problems for at-risk children.

Now, let me just ask you: Would you support an expansion in Medicaid like that which is proposed in the new Bradley Infant Mortality Bill?

Dr. ROPER. For the reasons cited by Governor Mabus, I believe that the States need flexibility. I think the States ought to improve their Medicaid Programs, and I believe they will.

Let me just respond to the body of your question.

Senator ROCKEFELLER. I would like you to respond to the question about the bill first.

Dr. ROPER. I am saying I am opposed. The Administration is opposed to mandating this coverage, but we ought to be giving the major incentive we can, which is the large Federal matching dollars, as inducement to the States. In my home State of Alabama, it is three Federal dollars for every one State dollar, and we ought to use moral suasion to get the States to do what they ought to do to improve their Medicaid Programs.

Senator ROCKEFELLER. That is sort of the history of the last number of years, getting the States to do what they ought to do; and the States are doing that. The question is: What can we do up here? This is not a group of governors you are giving testimony to.

Would you support legislation to cover catastrophic health expenses of children with severe medical problems?

Dr. **Roper**. It depends on the design of the program; the idea of further improving coverage of children is important, and we are about to give a report on a major group of children, the so-called technology dependent children, and suggest possible changes in the law there.

Senator **Rockefeller**. Do you think that we should be spending more money on prevention programs for children?

Dr. **Roper**. I sure do.

Senator **Rockefeller**. It is not recommended.

Dr. **Roper**. Prevention is a major focus of the activities in the Public Health Service, and prevention is the foundation of the early and periodic screening, diagnosis, and treatment program in Medicaid, which is discussed in my statement.

Senator **Rockefeller**. Mr. Chairman, I won't pursue it, and I know Dr. Roper is a fine person. We have talked on the phone. He is trying to do what is right, but I must say that I find his testimony void of constructive public policy suggestions.

I find the history of the Reagan Administration over the past several years, in terms of trying to help children, equally disappointing; and I think that point needs to be made.

Dr. **Roper**. I respectfully would reply by saying that, in financing programs, we pay for health care services. There are a number of innovative changes in delivery of health care services that have been demonstrated and reported on, largely by the Public Health Service and by my colleagues at the State level. Major improvements have been made in the last few years.

Senator **Rockefeller**. Thank you, Mr. Chairman.

The **Chairman**. Thank you. Senator Mitchell?

Senator **Mitchell**. Thank you, Mr. Chairman. Dr. Roper, many assert that the major preventable problem in children's health is prevention of low birth weight. Governor Mabus talked about it. Most all of the witnesses that have come before this committee on this subject discuss it.

There have been some indications that some women on Medicaid are having difficulty getting into early prenatal care. Is that correct? Do you have any indication of that?

If so, do you have any suggestions for us on how best to deal with that? I would ask Dr. Windom, and Dr. Hutchins if he chooses, to comment on the same questions, if they choose to do so, following your response.

Dr. **Roper**. Clearly, adequate prenatal care is associated with fewer low birth weight babies; and programs that are heavily focused on case management, that is getting women into prenatal care early on in their pregnancy and giving them the support services they need to have a successful pregnancy, do work.

Again, in my home State of Alabama, they did a study in 1985 that showed that, whereas the overall State infant mortality rate that year was 12.5 per 1,000 live births, women who were on Medicaid during their pregnancy had an infant mortality rate of nine per 1,000 live births. So, that kind of intervention does work through fewer low birth weight babies and a better infant mortality rate.

Senator Mitchell. And the other part of my question is: Are we doing that as effectively as we can? And if not, can you provide this committee with suggestions, either now or subsequently in writing, as to how we can more effectively do that?

Dr. Roper. Sure. Thank you, sir. We are not doing it as effectively as we can, primarily because we don't yet have a fully integrated system of programs dealing with the people at greatest risk; for example, WIC, Medicaid, the other programs often at the local level are not brought together and administered by the same agency.

When I was director of the local health department, we did that; and it does have an effect, if you can in a case management fashion bring all the services to bear to best benefit.

Senator Mitchell. And you will provide us in writing your suggestions as to how we can address this problem as a society more effectively since there appears to be a consensus, if not unanimity, on this being one of the most effective ways to deal with this serious problem?

[The information appears in the appendix.]

[The statement of Dr. Roper follows:]

Cost-Effectiveness of Case-Managed Prenatal Health Care

The Medicaid program has supported a number of projects to provide increased access to comprehensive prenatal care. Among the projects demonstrating the effectiveness of comprehensive, cost-managed care are those in California, Missouri, and South Carolina.

CALIFORNIA

The Obstetrical Access Pilot Project (1980–1984) tested in 10 clinical sites the hypothesis that the provision of early access to obstetrical services for low-income pregnant women would reduce subsequent morbidity of both infants and mothers. Services included health education, nutrition, and psychosocial assessments, in addition to prenatal, delivery, and postpartum services.

The key findings of the evaluation of this project were: low birthweight rate reduced from 7 percent to 4.7 percent for the demonstration group; and, a 2-to-1 benefit-cost ratio in the first year as a result of savings from neonatal intensive care services.

In 1984, the State of California approved legislation to authorize the enhancement of prenatal care to MediCal recipients on a statewide basis.

MISSOURI

Prenatal care and its relationship to Medicaid costs were studied by the Missouri Division of Health under a grant from the Health Care Financing Administration in 1983 and 1984. This project linked birth certificate records with Medicaid obstetrical and newborn records. The combined data set was used to study the obstetrical and newborn Medicaid costs associated with women who received preventive prenatal services as opposed to those who did not receive adequate services. The primary goal of the project was to determine if the prenatal care provided for the Medicaid mothers was cost beneficial.

Findings from the study suggest that there is a net increase in Medicaid costs associated with providing adequate prenatal care, but a reduction in low birthweight rates and a possible reduction in neonatal mortality among infants of mothers with adequate prenatal care.

SOUTH CAROLINA

Under a "freedom of choice" waiver (Section 1915(b) of Title XIX of the Social Security Act), South Carolina channels high risk pregnant women through a special program which includes: (1) case management services; (2) a full range of prenatal and intrapartum care; and (3) ancillary services (e.g., social work assessment, nutritional evaluations, health education, and delivery in hospitals with high risk units).

The State estimates that savings of $3.1 million will be realized over the two-year period of the waiver, through reduced neonatal intensive care costs and fewer children who require hospitalization or institutionalization.

Senator Mitchell. Dr. Windom?

Dr. Windom. Yes, Senator. In the Public Health Service, with our maternity and child efforts, we are doing a great deal in the education process. This is a very important aspect—to get people in communities aware of the importance the necessity of getting into a program of prenatal care; we have tried to reach people in order to do that.

Second, our community health centers and migrant health centers offer child health services which we also try to work with; and there is a broad expansion of programs that Dr. Hutchins can elaborate on, too.

Dr. Hutchins. I would agree with that. One of the reasons that we have problems is getting women into prenatal care, and that is a complex problem in itself; and the causes of low birth weight are complex.

We have been working with the National Governors Association, as was testified to earlier this morning, about implementing the optional XIX plans in the States, as Dr. Roper has talked about, and increasing the eligibility levels. But it is what happens after pregnant women register early. Early prenatal care is necessary to receive the acquired services.

Smoking, we know, is related to low birth weight; and so, smoking cessation programs need to be a part of prenatal care. We at MCH and the Centers for Disease Control have ongoing projects at the present time showing how smoking cessation might be incorporated into ongoing prenatal care.

We have a group of experts from outside the Government who are currently looking at the content of prenatal care to see what improvements and changes can be made that will affect the outcome of pregnancy.

Senator Mitchell. Would both you and Dr. Windom then do what I asked Dr. Roper, which is to provide us in writing with your specific suggestions on how we can more effectively address this problem?

Dr. Hutchins. Certainly.

[The information follows:]

Problem: How can we deal more effectively with the difficulty some women on Medicaid have in getting into prenatal care early?

Answer: Early entry into prenatal care is an important step in assuring the best outcome for pregnant women. Medicaid-eligible women, by virtue of their low income, have an increased risk in pregnancy and have a special need for early, appropriate, and continuous prenatal care. The Public Health Service (PHS) wholly supports the objective of early prenatal care for all women. The Office of Maternal and Child Health (OMCH) has funded demonstration projects across the country to implement models for promoting early care. OMCH currently supports an Institute of Medicine study on outreach and its role in ensuring early enrollment; a final report on the study's findings will be issued in the late spring of 1988.

Numerous barriers have been implicated in reduced access to care, including early care. These include financial barriers (not only for medical care reimbursement, as Medicaid-eligible women have, but also for transportation and child care); lack of an awareness of the importance of prenatal care; lack of available providers (exacerbated by the malpractice issue); and others. The PHS has a broad initiative, encompassing public and professional education, coordination among all health and health financing agencies, and linkages with local and State organizations to identify, examine and address all access problems for pregnant women.

To specifically focus on the needs of Medicaid-eligible women, the PHS supports a joint project of the National Governors' Association, the OMCH, and the Division of Primary Care Services which provides assistance to States in implementation of Medicaid services for pregnant women and infants. This project has provided technical assistance regarding case management, a mechanism which assists clients receive timely and appropriate services, and has issued a paper on increasing provider participation. In addition, staff of the OMCH and the Health Care Financing Administration and representatives from respective State agencies work together through the MCH/Medicaid Directors Technical Advisory Group. This group has identified and shared model practice relationship to foster coordination of services for pregnant women and infants.

Senator MITCHELL. Thank you very much. Mr. Chairman, thank you.

The CHAIRMAN. Thank you, Senator. Senator Baucus?

Senator BAUCUS. Dr. Roper, I want to thank you for coming to Montana, as you did a short while ago, to address rural health care problems. I know the folks that you met with very much appreciated your coming.

A related issue obviously is medical malpractice in obstetrics. I know the Administration has set a model, a Tort reform statute, to the States in an attempt to address the problems of medical malpractice and the number of obstetricians who are leaving the practice.

Do you honestly think that that plan is going to get anywhere or that States are going to adopt it? Is it going to address the problem in any significant way?

Dr. ROPER. I honestly do.

Senator BAUCUS. How many States have adopted it so far?

Dr. ROPER. My home State of Alabama, with Governor Hunt's leadership, enacted Tort reform last year, in 1987. It was the governor's number one priority, and he got it through the legislature. It is difficult to do.

Senator BAUCUS. Have the rates come down in Alabama?

Dr. ROPER. They have stabilized; they haven't gone up. Alabama has the same problem you do; half of our counties don't have doctors delivering babies in those counties largely because of Tort liability problems. Secretary Bowen, as you know, has this as one of his major priorities, urging the States to pass legislation.

I guess I am pragmatic on this. If the States don't get it done, I guess the Federal Government will have to step in.

Senator BAUCUS. Why not also raise the reimbursement rate—the Medicaid reimbursement rates—to some degree?

Dr. ROPER. That is what Alabama has done as well. They increased the amount they would pay for a delivery so that it will attract doctors. They are more willing now to participate in the program.

Senator BAUCUS. Do you think a combination of both increased reimbursement rates as well as State medical malpractice and Tort reform will be more effective?

Dr. ROPER. Let me try an idea on you. If the Federal Government really wants to give some leverage to the States, you could do as you do on highway funding. And you could say to the State of Montana: If Montana is not willing to reform its Tort laws and it persists in wasting Federal dollars in its Medicaid Program, you will cut the Federal matching rate for Medicaid to that State.

Senator **Baucus**. I suspect we would hear the States in a serious manner on that one.

I understand that Blue Cross/Blue Shield and the March of Dimes have an active program; it is "Beautiful Babies Right From the Start."

Dr. **Roper**. Yes.

Senator **Baucus**. This is a public awareness program. If the cost of benefit analysis in prenatal care is so beneficial, I am wondering what efforts HHS might undertake to let women know what programs are available and what services are available so that they are likely to utilize them? It seems to me that this might be an area where some advertising would do a great deal to make some sense.

Dr. **Roper**. It sure is.

Senator **Baucus**. What are you doing to get the word out?

Dr. **Roper**. I think my colleagues to my left are the experts there. A number of States have done it. In Alabama, we had a program called "Better Bama Babies."

Senator **Baucus**. What can the Federal Government do to encourage this?

Dr. **Windom**. We are doing a lot, Senator, in the area of Healthy Babies, Healthy Mothers, to disseminate the information by communication, through public service announcements, through many media outreaches to communities, and through the medical clinics and centers—to get the message out to these individuals. Dr. Hutchins may want to expand upon that.

Dr. **Hutchins**. "Healthy Mothers, Healthy Babies," the Alabama chapter that Dr. Roper just referred to, is a coalition of about 80 organizations, which is doing a considerable amount in public awareness. Part of it is through committee work where approaches to low income underserved women has been looked at, promotion of breast feeding, promotion of general health care.

The "Healthy Mothers, Healthy Babies" organization has State chapters in every State, and the public awareness parts of it are done through professional organizations and voluntary organizations, as well as public agencies.

Senator **Baucus**. Is there a Federal initiative, I mean, in an aggressive way?

Dr. **Hutchins**. Yes, this is.

Senator **Baucus**. Do you have an analysis to determine whether it is working?

Dr. **Hutchins**. It would be very difficult to evaluate that type of approach.

Senator **Baucus**. Or is this just good intention?

Dr. **Hutchins**. I think it is more than good intention in that things are happening because of it. It is a difficult program to evaluate because so much of it is being done by different agencies, different collections of people within the State and communities.

Senator **Baucus**. Thank you.

The **Chairman**. Thank you, Senator. Senator Chafee?

Senator **Chafee**. Thank you, Mr. Chairman. I am intrigued, Dr. Roper, with the "Better Bama Babies." I hope that program is successful. Let me ask you a question. In a society where there is considerable stability and there is some discipline like in, say, Japan, for instance or perhaps Sweden, what is the figure that they achieve in their number of infant deaths per birth—per 1,000 births? Do you know what that is? In other words, what goal can we shoot for?

Dr. **Roper**. Dr. Hutchins is the expert, but I think most observers believe that five or six deaths per 1,000 live births is about the minimum that we can shoot for.

Senator **Chafee**. And what are we at now, nationwide?

Dr. **Windom**. 10.6.

Senator **Chafee**. Ten? So, we can cut that in half presumably, all things being perfect?

Dr. **Windom**. The other problems, Senator, are that there is not a uniformity of reporting in foreign countries, which is a factor and other countries deal with their social and economic problems differently. So, there are some discrepancies in that type of reporting.

Senator **Chafee**. I appreciate that, but they may favor us as well as penalize us. What are we doing about the reimbursement levels for those who take Medicaid patients—Medicaid reimbursement? As I understand it, what Dr. Roper was saying is that that is left to the States but at the same time, haven't you got some rates on that subject that the reimbursement levels must be enough to ensure physician participation?

Dr. **Roper**. Yes, sir.

Senator **Chafee**. That doesn't seem to be happening to the extent that I believe it should—in our State, anyway. Are you publishing those regulations? And what are you doing to enforce them?

Dr. **Roper**. As a part of the State plan that they publish annually, they have to do exactly as you said, have rates sufficient to attract enough doctors and to run the program. Now, we don't set specific rates as a floor that they have to be above but we do monitor what rates they pay their physicians.

Senator **Chafee**. Have you gotten any experience anywhere with the reform of the physicians' malpractice insurance premiums situation? I know in you State that they just adopted it last year. Who has it, and is it working?

Dr. **Roper**. Yes, sir. I have a good State to cite. Indiana. The Governor of Indiana led a fight to reform the Tort laws in 1975, and Governor Bowen—now Secretary Bowen—had a major impact because Indiana's rates are much lower than the rest of the country.

Senator **Chafee**. Is that right? And thus, is there greater physician participation? What we are finding in our State is not only are young doctors not going into obstetrics, but the doctors who are 60 years old or so are saying forget it; it is not worth the hassle. And they are just getting out. So, we are losing at both ends: early retirements, if you would, from obstetrics—not necessarily as physicians—and young doctors not coming in.

Now, in Indiana's experience as a result of reforms, is there any data we have that can say that they are having greater physician participation, as obstetricians?

Dr. **Roper**. I don't know, but I would be glad to supply that for the record.

[The information follows:]

PHYSICIAN PARTICIPATION IN INDIANA

In 1975 the Indiana legislature passed a new Medical Malpractice Act. Under this law, health professionals are able to participate in the State operated Patient Compensation Fund. By participating in the fund, health care professionals are eligible for increased malpractice coverage and their liability is limited to $500,000. A health professional's participation is initiated by paying his/her insurance agent a 125% surcharge on a medical malpractice insurance policy.

For example, a physician purchases $100,000 insurance from a private carrier and pays that carrier an additional 125% above the premium amount. The physician is then guaranteed an additional $400,000 coverage by the Patient Compensation Fund. The insurance agent forwards the surcharge payment to the State fund. Maximum coverage under the fund is $500,000.

The modest cost and the reduced liability has led to excellent participation in the fund. Approximately 75% (30,000) of Indiana providers belong to the Patient Compensation Fund.

An important feature of this law is that all types of health care providers, (e.g. registered nurses, midwives, etc.) can participate.

The Indiana Patient Compensation Fund has resulted in what are reportedly some of the lowest malpractice insurance rates in the country. Furthermore, unlike situations in other States, there is no severe provider access problem in any portion of the State for any type of provider.

The Indiana Department of Insurance which manages the fund forwards claims against the fund and payments from the fund to the Indiana Medicaid agency which assists that agency in its efforts to recover funds from liable third parties. Actual numbers on increased physician participation in the Medicaid program as a direct result of this legislation are not readily available.

Dr. WINDOM. I would say that they are because there are other States that are having greater problems, and the decline is greater in those States. Let me point out, sir, that 1976 is when this really began, when the malpractice crisis occurred in the first place. And there has been a gradual progression of doctors leaving because of the increasing problems.

But when Secretary Bowen did initiate his initiative with the task force, a publication was out about three or four months ago and sent to the States. For example, three weeks ago in the State of Florida, which is my home State, we had some members of Dr. Bowen's staff who went to Florida to help the State physicians and those working toward this issue and came up with Tort reform in several bills in Florida, for example, the "Bad Baby" bill, which means that a bad outcome does not automatically mean malpractice and a no-fault type of program is involved there.

So, this has been model legislation that already has shown an effect in one State, for example.

Senator CHAFEE. I would choose a happier title for it than a "Bad Baby" bill.

Dr. WINDOM. I would, too, sir. [Laughter.]

Senator CHAFEE. It is not the baby's fault.

Dr. WINDOM. I agree with that, but that is a sort of term that has been in circulation for many years now.

Senator CHAFEE. I think they may need some polishing up with that. [Laughter.]

All right. I have a final question, Mr. Chairman. The data that I am giving from the experience in my home State is empirical; I don't know whether it is accurate or not, and whether they are flukes or not. What I am asking is, are the pediatric societies reporting that these experiences are occurring—fewer doctors going in and earlier retirements—in pediatrics?

Dr. ROPER. You said pediatrics do you mean pediatrics or obstetrics?

Senator CHAFEE. I meant obstetrics; excuse me.

Dr. WINDOM. The number entering has not declined. Those are young students going into medical school, and that is at about the same rate. But the ones getting out of practice is declining.

Senator CHAFEE. You mean they are getting out earlier?

Dr. WINDOM. As for those in medical school or wanting to enter medical school or residency programs; that level has not decreased. But physicians out in practice have decreased.

Senator CHAFEE. The data on those in my State, anyway, is dramatically declining—that is, those going into it.

Dr. WINDOM. It varies across the country.

Senator CHAFEE. Yes, thank you. Thank you, Mr. Chairman.

Senator ROCKEFELLER. Senator Daschle?

Senator DASCHLE. Thank you, Mr. Chairman. I guess I would start by saying that I share some of the disappointment expressed by some of my colleagues with regard to the lack of specifics in the Administration's testimony this morning. You are both very dedicated and well-intentioned leaders in the health community and certainly in this Administration, but I find your testimony far short of the mark with regard to specifics.

I was going through my speeches for a lot of different reasons a few weeks ago, and I found a speech that I gave in 1977 on health care. In that speech, I used the figure that five million children did not have access to health care, and that in the United States we were fifteenth in infant mortality in the world today. That speech was given in 1977.

Today, I understand we have six million children who don't have access to health care—six million children. We rank sixteenth or seventeenth in infant mortality. So, in the last ten years, we have actually slipped from the ranking we had ten years ago.

The year 2000 is twelve years away. And I would ask if you could specifically—not orally now, but for the record and in a letter to me—outline your proposals and your expectations in the next twelve years, how you think we will rank in the year 2000 with regard to access to health care for children and with regard to the ranking the United States will have in infant mortality in the year 2000? Would you do that?

Dr. WINDOM. We will be happy to do that for you.

Senator DASCHLE. I would like some specifics.

Dr. WINDOM. Sure.

[The information follows:]

DEPARTMENT OF HEALTH AND HUMAN SERVICES,
PUBLIC HEALTH SERVICE,
Washington, DC.

Hon. THOMAS A. DASCHLE,
U.S. Senate, Washington, DC.

DEAR SENATOR DASCHLE: This letter is in response to your questions to me for the record when I testified before the Senate Committee on Finance, March 23, 1988 on Child Health issues.

First, at this time, we cannot project an infant mortality rate for the year 2000 because the Department is still in the process of defining the Year 2000 Health Objectives for the Nation. The process for setting objectives involves the collection and analysis of health data from surveys followed by solicitation of public comment.

The United States ranked 17th among Western countries in 1986. Since there are so many uncontrollable variables in projecting ranking of countries, we cannot project what ranking the U.S. would have in the year 2000 even after we complete the process of determining the objective. Further, rankings and comparisons of countries on infant mortality rates are complicated by differences in definitions and reporting procedures.

With regard to children's access to health care in the year 2000, it is again difficult to determine what the situation will be. From a study conducted by the Office of Technology Assessment, it was found that, in 1986, 63 percent of the 45 million children in the U.S. were covered by private health insurance. For those children who did not have health insurance, Federal programs of direct care such as the Maternal and Child Health Services block grant program, the Head Start program, community health centers, migrant health centers, and the Indian Health Service are especially important. These programs will continue to meet the needs of those children who are not covered by private health insurance.

Sincerely yours,

ROBERT E. WINDOM, M.D.,
Assistant Secretary for Health.

Senator **DASCHLE**. Second, my greatest concern with regard to health care deals with health care in rural areas. I was told a couple of weeks ago that a child experiencing a medical emergency in a rural area has only a 25-percent chance of survival compared to someone experiencing a similar emergency in an urban area. That really troubles me if that is the case.

I think it probably is the case, at least in South Dakota. Statistics have borne that out. Yet, over the last ten years, we have seen a 30-percent decline in community health centers, those facilities that are often the only facilities available to mothers and young children—a 30-percent decline in those.

And this year, we see a 30-percent cut in the National Health Service Corp's budget request. In light of those kinds of developments—a 30-percent reduction in the number of facilities in rural areas to assist these children; a 30-percent cut in the budget—how can we possibly give any assurance to someone living in a rural area, especially a young child without any access to health care, that those statistics—that 25-percent survival rate, relatively speaking—will ever improve?

Dr. **WINDOM**. Senator, we do have a new initiative in the Department, in the Health Resources and Services Administration for rural health—with an entirely new program focused upon that, looking toward this very problem that you refer to. We realize that that does occur, and we also realize the factors of getting to the care in time and also the problems of having a full, complete complement, for example, of neonatology and all the sophisticated services in the rural area. They just aren't there and won't be there, but we are trying to work out the best solutions to that problem.

We will be glad to provide the information about that for the record.

[The information follows:]

The Office of Rural Health was established to provide a focal point within the Department for coordinating nationwide efforts to strengthen and improve the delivery of health services to populations in rural areas. The Office will coordinate rural health activities within the Department of Health and Human Services and across other related Federal agencies. The Office will also work closely with State governments, foundations, private associations and other groups to help focus attention on rural health care issues and problems. In addition, the Office will collect and analyze information on the special problems of rural health care providers and establish a clearinghouse to collect and disseminate the latest information on the delivery of services in rural areas. The new Office will have between eight and ten employees, including some from the Health Care Financing Administration.

Senator **Daschle**. How much of a factor in all of these solutions do you think money really is?

Dr. **Windom**. Money is a part of it, but it is certainly not all of it. And again, it is a matter of——

Senator **Daschle**. If you had to guess, what would you say? What percent of the problem is related to money?

Dr. **Windom**. In rural health? The total problem of the overall health care?

Senator **Daschle**. Right.

Dr. **Windom**. I would have to estimate it is certainly less than half of the problem.

Senator **Daschle**. Less than half?

Dr. **Windom**. I would say in my own estimation, sir.

Senator **Daschle**. A final question in the time that I have remaining: It has been demonstrated one dollar spent on immunization saves $10.00 later on in actual health care delivery costs.

In the last few years, we have actually declined, as I understand it, in the level of immunization for children under the age of two, despite this fact. If that is the case, how do you see the role of immunization in the future?

First, do you agree with the tremendous impact that immunization can have in cost deferral later on? And second, if those factors are relatively accurate, how can we then justify reducing the level of cost effective immunization?

Dr. **Windom**. Immunization support certainly must be continued, and the problem is getting those children in the first year or two into the system to get immunized. By the age of six, at entry to school, that number is virtually 99 percent. But we are short on the first two years, and this is an area where we are focusing particular attention also, trying to get the individuals into the system to be immunized.

Senator **Daschle**. I wish I had more time. That wasn't the answer I was looking for, but thank you, Mr. Chairman.

The **Chairman**. You certainly can give him a written question and ask for a written answer to it.

Senator **Daschle**. I would like to pursue that, if I may.

The **Chairman**. All right.

[The questions follow:]

QUESTIONS FROM CHAIRMAN BENTSEN TO HHS WITNESSES

Hearing on Children's Health Care Issues
Senate Finance Committee
March 23, 1988

Dr. Windom:

1. Like ventilator dependent children, other children dependent on high technology may be able to receive care in an outpatient setting. The Office of Technology Assessment has recommended expanded home coverage for children who must be intubated (fed a liquid diet through a tube). Is the Maternal and Child Health program funding any demonstrations to determine whether home or community-based care is feasible for these or other technology-dependent children? Where, and what funding level is involved?

2. I understand that much progress has been made in coordinating services provided by Medicaid and the Maternal and Child Health programs. What further steps can we take in this area -- in particular, are any improvements needed in the uniformity and substance of reporting requirements for the Maternal and Child Health program?

3. Several of our witnesses today have submitted statements indicating that Medicaid enrollment procedures raise significant barriers to access to prenatal care for pregnant women. In the 1986 Reconciliation Act, Congress made possible a determination of "presumptive eligibility" for pregnant women to expedite their application to Medicaid. Has this approach been successful? What else could be done to improve access to prenatal care for Medicaid-eligible women?

Dr. Roper:

Several of our witnesses today have submitted statements indicating that Medicaid enrollment procedures raise significant barriers to access to prenatal care for pregnant women. In the 1986 Reconciliation Act, Congress made possible a determination of "presumptive eligibility" for pregnant women to expedite their application to Medicaid. Has this approach been successful? What else could be done to improve access to prenatal care for Medicaid-eligible women?

QUESTION FROM CHAIRMAN BENTSEN TO DR. WILLIAM ROPER

Hearing on Children's Health Care Issues
Senate Finance Committee
March 23, 1988

Q. Several of our witnesses today have submitted statements indicating that Medicaid enrollment procedures raise significant barriers to access to prenatal care for pregnant women. In the 1986 Reconciliation Act, Congress made possible a determination of "presumptive eligibility" for pregnant women to expedite their application to Medicaid. Has this approach been successful? What else could be done to improve access to prenatal care for Medicaid-eligible women?

A. Twelve States have adopted the presumptive eligibility coverage option. This option allows a pregnant woman who appears to meet Medicaid eligibility requirements to be covered from the moment she walks into an approved provider's office, seeking care. The State guarantees approved providers that it will cover those expenses even if the woman is determined ineligible after the formal Medicaid application process. Assuring that bills will be paid for initial visits reduces the woman's and the provider's uncertainty over payment and increases the likelihood that the woman will seek care and that the doctor will continue to provide care.

Some States have initiated other programs to simplify the Medicaid application process. Several State agencies have placed Medicaid eligibility workers at major hospitals, clinics, and large providers' offices to complete the Medicaid applications on site, when the woman comes in for care. Seventeen States have dropped the assets test for pregnant women. Eliminating this test considerably speeds up processing of the Medicaid application because investigating the assets statement is a lengthy process.

QUESTION FROM CHAIRMAN BENTSEN TO DR. WINDOM

Q: I understand that much progress has been made in coordinating services provided by Medicaid and the Maternal and Child Health programs. What further steps can we take in this area -- in particular, are any improvements needed in the uniformity and substance of reporting requirements for the Maternal and Child Health program?

A: States receive annual allocations of maternal and child health block grant funds based on the submission to the Federal agency of a Report of Intended Expenditures which describes how they will use their funds. The general service and program-related activities to be supported with these funds are contained in the law and implementing block grant regulations. There is no standard format which requires that States report uniformly on the programs supported. The philosophy of block grants is that States have wide latitude and flexibility in administering their block grant programs and in identifying the maternal and child health related priorities which exist within their particular jurisdiction. It would therefore not be appropriate to require all States to adhere to a uniform set of program reporting requirements. What applies in a very significant way to one State may be almost irrelevant in another. For example, States with large urban population concentrations face much different health care delivery requirements from those which are predominantly rural in nature. States do report some uniform data through the Public Health Foundation Reporting System which is run by the Association of State and Territorial Health Officials. This reporting is done on a voluntary basis.

Q: Like ventilator dependent children, other children dependent on high technology may be able to receive care in an outpatient setting. The Office of Technology Assessment has recommended expanded home coverage for children who must be intubated (fed a liquid diet through a tube). Is the Maternal and Child Health program funding any demonstrations to determine whether home or community-based care is feasible for these or other technology-dependent children? Where, and what funding level is involved?

A: The Bureau of Maternal and Child Health and Resources Development is funding a number of demonstration project grants to determine the feasibility of home and community-based care for children who are technology dependent and/or medically fragile. These projects include such examples as:

a. A comprehensive service delivery model at the home and community levels conducted at the University of Wisconsin for 50 to 75 medically fragile infants and children with associated feeding problems, many of whom must be intubated.

b. A continuing education project for an interdisciplinary group of health professionals project at the University of Kansas Medical Center to upgrade nutrition-related interventions in the home for children with special health care needs;

c. Developing models of home health care for technology dependent children and their families in Illinois, Louisiana, Maryland, and Florida;

d. The promotion of parent/professional collaboration to result in services that are family-centered and close to home, in Massachusetts and the District of Columbia; and

e. A mixture of projects which focus on home health care management systems, community-based interagency efforts, policy analysis issues, family and community-based care issues for culturally diverse population groups in States such as Michigan, Montana, and New Mexico.

Approximately $6 million is currently earmarked during FY 1988 for special demonstration projects of regional and national significance in this special area of concern.

Q: I understand that much progress has been made in coordinating services provided by Medicaid and the Maternal and Child Health programs. What further steps can we take in this area -- in particular, are any improvements needed in the uniformity and substance of reporting requirements for the Maternal and Child Health program?

A: States receive annual allocations of maternal and child health block grant funds based on the submission to the Federal agency of a Report of Intended Expenditures which describes how they will use their funds. The general service and program-related activities to be supported with these funds are contained in the law and implementing block grant regulations. There is no standard format which requires that States report uniformly on the programs supported. The philosophy of block grants is that States have wide latitude and flexibility in administering their block grant programs and in identifying the maternal and child health related priorities which exist within their particular jurisdiction. It would therefore not be appropriate to require all States to adhere to a uniform set of program reporting requirements. What applies in a very significant way to one State may be almost irrelevant in another. For example, States with large urban population concentrations face much different health care delivery requirements from those which are predominantly rural in nature. States do report some uniform data through the Public Health Foundation Reporting System which is run by the Association of State and Territorial Health Officials. This reporting is done on a voluntary basis.

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QUESTIONS FROM SENATOR BAUCUS TO DR. WINDOM

Question: Please elaborate on the national program you identified for making educational and prenatal services available to pregnant women.

Answer: The program referred to is the Healthy Mothers, Healthy Babies Coalition. The Surgeon General's Workshop on Maternal and Infant Health, in December 1980, recommended that the Surgeon General "...use the influence of his office to develop a strategy of public information and education to promote the recognition of the great value to the Nation of healthy pregnant women and infants." Shortly thereafter, the Public Health Service and the March of Dimes, together with the American College of Obstetricians and Gynecologists (ACOG), the American Academy of Pediatrics, the Parent Teachers Association and the American Nurses Association, sponsored an organizational conference out of which grew the Healthy Mothers, Healthy Babies Coalition. Thirty-six national voluntary, professional and government organizations participated at first; there are now 92 such organizations in the National Coalition.

1. What is the Federal budget for this program?

Answer: The Office of Maternal and Child Health has for the past four years given a grant to ACOG (which donates space in their national offices) to support the Healthy Mothers, Healthy Babies Executive Secretariat. In FY 1988, this amounted to $88,883.00, which paid the salary of a full-time director, a part-time secretary, the newsletter and other communication instruments, travel and other miscellaneous costs. (Prior to this grant, staff support for the Coalition was provided directly by the Office of the Assistant Secretary for Health.)

2. What activities does it support, in how many States?

Answer: The Executive Secretariat supports the development of Healthy Mothers, Healthy Babies Coalitions at the State level, the sharing of information among State Coalitions, and the convening of statewide conferences. It also sponsors a national conference every other year, and provides ongoing support to the activities of the Coalition's subcommittees.

State Coalitions have been established in all 50 States, the District of Columbia, Puerto Rico, the Virgin Islands and Guam. In addition, in some States there are a number of local Coalitions centered in larger cities; California, for example, has 13 such local Coalitions.

The major work of the National Coalition is done in subcommittees. These are: Adolescent Pregnancy, Breastfeeding Promotion, Genetics, Injury Prevention, Low-Income, Oral Health, Policy, Substance Use and Pregnancy, and National Conference Planning. Packets of educational materials have been assembled, publications developed, surveys conducted, and public awareness campaigns held through the efforts of these subcommittees. Samples of these products are enclosed.

3. What is being done to evaluate the success of these activities and to share the result of these evaluations with other States?

Answer: The Executive Secretariat publishes a quarterly newsletter which provides an opportunity for State Coalitions to share information. It compiles and distributes to State Coalitions news clips from throughout the country of events involving Healthy Mothers, Healthy Babies. It distributes to the State Coalitions policy materials and sample products developed by the various States.

The Executive Secretariat does attempt to evaluate the products produced by Healthy Mothers, Healthy Babies. The evaluation of the Substance Use information packet and the evaluation of the Fourth National Meeting are enclosed. At the present time the Executive Secretariat is awaiting responses from a questionnaire it submitted to the State Coalitions, which will measure the breadth of representation on the Coalitions, the scope of their activities and their successes. When this data is compiled, we will send you a copy of the report.

4. Do any of these programs contain outreach efforts specifically targeted toward those who may be eligible for Medicaid but may not know about the program or know how to qualify?

Answer Many of the activities of Healthy Mothers, Healthy Babies are focused on low-income, underserved women to bring them into early prenatal care and achieve more successful pregnancy outcomes. A Compendium of Program Ideas for Serving Low-Income Women, which was published in 1986, drew from 1500 respondents the most promising and successful outreach efforts; it has been widely circulated within the Healthy Mothers, Healthy Babies family and to thousands of others engaged in serving low-income women. With adoption of the Medicaid option which makes access to prenatal care more available, the strategies described in the compendium should be extremely useful.

In addition, the Executive Secretariat will be producing leadership training workshops for State Coalition personnel in which the issues around expanded Medicaid-eligibility will be fully explored so that State people can maximize the benefits of this new provision.

Storkline, a statewide toll-free telephone referral service initiated by the Alabama Healthy Mothers, Healthy Babies Coalition, received a National Achievement Award from the National Coalition last year. Storkline assists low-income pregnant women in locating prenatal care and hospital delivery services, and provides callers with prenatal care information Other successful outreach campaigns have been similarly recognized in the past. These national awards are presented on Child Health Day in a Washington, D.C. ceremony and are well publicized throughout the country.

The CHAIRMAN. Senator Wallop?

OPENING STATEMENT OF HON. MALCOLM WALLOP, A U.S. SENATOR FROM THE STATE OF WYOMING

Senator **WALLOP**. Mr. Chairman, thank you. It strikes me that there are two sets of problems; one is the Tort reform, which this Congress and previous ones have refused to do anything serious about. The second one is, of course, the administration of HCFA itself and not just referring now specifically to the almost hysterical despair that exists within the medical community of Wyoming, about the facelessness of HCFA and the inability to appeal decisions on compensation.

So, on the one hand, you have doctors leaving at both ends; on the other side, we have doctors who are wondering how they are going to participate in yet another federally funded program when the ones in which they are presently participating are so frustrating to them.

Though I am terribly, strongly in favor of what we are doing here, I am afraid that, no matter what we do, we are not going to have any doctors participating unless we can solve some of those problems. Let me just give an example.

There was a physician in Cody, Wyoming who had a patient in an intensive care nursing facility. The physician is required by Medicare to make periodic visits. He made a visit, left town briefly, and two days later his patient had a medical emergency. Another physician responded and submitted a bill to Medicare. The patient's physician was denied payment for his original visit because the patient had two visits in a time period when Medicare only permits one. It doesn't matter whether the visit was a response to a medical emergency.

Neither that physician nor I can understand this logic. What is he to do, and what am I to tell the medical community of Wyoming when all they get is computer-generated responses to this over a relatively small bill, $25.00?

It isn't the $25.00; it is the principle that this man was accused of cheating the Government when he responded to a medical emergency.

Dr. **ROPER**. The frustration of the physician you cite is very real, Senator. I feel it myself in going around talking to my physician colleagues. I will share with you a specific point. I would be glad if you give me a specific case, to have my staff look into it; but it does not make sense for us to make those kinds of bone-headed decisions. That doesn't make us look good in attempting to manage a program.

But I think that is part of a much larger problem; and that is, we, the Federal Government—both you in the Congress and we in the Administration—are trying to micromanage from Washington an entirely too complex system already, out there across the country.

When we are faced with a program, Medicare, that serves 31 million people, 500,000 doctors, 16,000 nursing homes, 6,000 hospitals, 10 million admissions to hospitals each year, we have to make rules; and as you well know, rules don't fit individual circumstances. And that is why, I think, the direction we are headed of further micromanagement is entirely the wrong direction.

Senator **Wallop**. Doctor, I would agree with that. Mr. Chairman, I have other questions with regard to this. I appreciate your offer to look into that, and I have a couple of others from the State.

Dr. **Roper**. Sure.

Senator **Wallop**. But it seems to me that, if we are going to make a success out of expanded access for children's medical services, one of the keys to the access is the participating physician.

Dr. **Roper**. Sure.

Senator **Wallop**. Unless we get a handle on that, we have really got a catastrophe.

Dr. **Roper**. Doctors have to believe that they are going to be paid fairly, not going to get sued frivilously, and will be able to do their job in a professional way without unreasonable hassle from us in the Federal Government. If we can't assure that, we won't have a program in the future.

Senator **Wallop**. I have another case here of a physician regarding charges; and he has not changed his fee since 1984, but his fee was disallowed. And they can't get an answer to what is taking place in that area.

So, if you would be kind enough to get somebody on your staff to look at some of these, I and the physicians in Wyoming would appreciate it; and maybe we might get some participation.

Dr. **Roper**. Sure, we will be glad to do that.

Senator **Wallop**. Thank you, Mr. Chairman.

The **Chairman**. Senator Danforth?

Senator **Danforth**. Dr. Windom, you said that the minimum infant mortality rate was about five or six deaths per 1,000 live births and that we have about 10 in 1,000. That is infant mortality—babies who were either born dead or died in their first year. Is that correct?

Dr. **Windom**. Yes, the first year.

Senator **Danforth**. Die within their first year?

Dr. **Windom**. Yes.

Senator **Danforth**. All right. Now, in addition to that, there are a number of babies, many of them I think, that are born very small and that are kept alive by previously impossible means. Isn't that right?

Dr. **Windom**. Yes, sir.

Senator **Danforth**. Do most of those turn out to be normal, healthy children?

Dr. **Windom**. Many do not. We can't give you the exact figure at this point, but many of them don't survive, though, even after several months; many of them do turn out healthy, but others certainly have consequences of that very low birth weight.

Senator **Danforth**. And if a baby is born with a low birth weight, the chances of that baby having complications later on are increased. Is that right?

Dr. **Windom**. Yes, that is right, from that of a normal birth weight, a normal child.

Senator **Danforth**. Is it costly to care for a baby who is born prematurely?

Dr. Windom. Yes, sir. Today, with all the technological advances that have occurred, babies are born weighing a pound and a half to two pounds even; that was never known to occur before all these advances have been made. Consequently, they are in neonatal intensive care units, costing up to maybe $60,000 to $100,000 just to take care of those infants during the weeks and months after birth and, often then, they may not survive. But if they do, it has been shown to require a great deal of time before they ever get out of the hospital.

Senator Danforth. If prenatal care were better than it is now, would we not only improve the infant mortality rates but also improve the health of those babies who are born prematurely and further helped with the cost of health care?

Dr. Windom. Exactly. That is the whole key—to get the mother with good prenatal care and not abusing any substances, which aggravate the problem, and following the proper precautions—that will solve many, many subsequent difficulties.

Senator Danforth. There are in the District of Columbia anyhow, television commercials that I see from time to time that make the effort of reaching out to pregnant women and telling them that they should take care of themselves and see a doctor and so on. Is that unusual in the District of Columbia? Is this a national program? And if it is not a national program, should it be a national program?

Dr. Windom. It is a national program, and the "Healthy Mothers, Healthy Babies" effort that we just mentioned includes the cooperation of many groups that are interested in the common effort. So, we are putting on these types of educational outreach programs in many communities.

Senator Danforth. Should this be expanded?

Dr. Windom. It is being expanded, Senator, and I am sure it will continue to be expanded because those people who are behind the effort are very committed and dedicated toward that goal; they have the initiative and the perseverance to reach out, explaining the benefits.

Senator Danforth. I know that, as of about six months ago or so, it was not available in St. Louis. I know that there have been meetings that have been going on in the St. Louis area to create such a program; but I inferred from that that this is not something that is national in scope, and maybe it is something that we could improve on.

Dr. Windom. We need to get the message out, and we will certainly be glad to offer what we can to the people in St. Louis who are also behind the effort.

Senator Danforth. I would think that it would be absolutely essential to do this.

If you had a commercial, if you were the person—the face on the television—what would you say to pregnant women? What is the important message to get out to them?

Dr. Windom. The important message is to seek medical attention from your physician as soon as you are aware of your pregnancy and get the direction and guidance that your physician or your health clinic can provide for you, that you immediately stop the abusive use of any tobacco, alcohol, and other substances—or drugs of other types—because those can cause an impact and be a deterrent to having a healthy baby.

So, we would want that mother to get into the system of health care provision as early as she can and follow that guidance and do whatever things she can to maintain her good health during the pregnancy.

Senator **Danforth**. Those are the keys to it? Stop smoking? Stop drinking? Stop abusing drugs? And see a doctor?

Dr. **Windom**. Right. And maintain good, adequate nutrition. Exercise.

Senator **Danforth**. I have only one other question, Mr. Chairman. If we are telling mothers to seek medical attention, is that universally available now?

Dr. **Windom**. In one source or another, sir, it certainly is. If the mother can afford it, she has many opportunities. If she cannot afford it, she still has opportunities through clinical services at the local health department, and they can advise her and guide her, if she is at all interested.

If she is not interested—we find that that is our big problem—to get that mother aware and interested to get into the system. She can do that.

Senator **Danforth**. But your testimony is that anywhere in the country, if a woman is pregnant and totally impoverished, medical care is available to her today?

Dr. **Windom**. Yes, sir. It can be arranged wherever she lives.

Senator **Danforth**. So, the problem is basically informational and motivational?

Dr. **Windom**. Exactly, and the awareness of how to go about getting that help.

Senator **Danforth**. Thank you.

Dr. **Roper**. Mr. Chairman, I would like to follow up on Senator Danforth's comments if I could. It is certainly true that the relative availability of prenatal services in various parts of the country differs; some places it is easy for a woman to get prenatal services; in others, it is terribly hard. I think that is a fact of life, and that is why I said in my statement that southern States in particular, which have had very poor systems, ought to remedy that situation.

Senator **Danforth**. Mr. Chairman, if I could, it would seem clear to me that our goal should be to make medical care universally available to pregnant women; and the second goal should be a very concerted outreach program to inform and motivate pregnant women as to what steps they should take to deliver healthy babies. I mean, that would be my view. Is that the Administration's view also?

Dr. **Roper**. Yes, but let me just add a more philosophical point, if I may. It seems to me we have had an unfortunate dysfunction in our debate over the problem of infant mortality.

On the one hand, there have been some arguing that this was such a problem, an embarrassment for the nation, given our comparison to other nations, that we need to put much more money into programs to fund public services, et cetera.

On the other hand, some people have said that this is a question of individual responsibility; women and men ought to avoid becoming pregnant. They ought not to engage in drug abusing habits, drinking, smoking, et cetera. This is an individual responsibility matter; let's not talk about more money and public programs.

I think you have to do both. The people who believe in more money and public programs ought not to gloss over the fact that there is an important role for individuals taking control of their own lives and engaging in healthy behavior, and then people who are promoting individual responsibility have to recognize the importance that we as a society have for caring for those who can't afford to pay for it.

Senator **Danforth**. Thank you. Mr. Chairman, I have a statement I would like to have put in the record, if I might.

Senator **Daschle**. Without objection. Senator Danforth your comment, I think, is absolutely correct, that our goal should be universal access; but I think if we are going to accomplish that goal, we have to have the facts. And I must say, Dr. Windom, you are the expert. You and Dr. Roper are the ones with the information. We are just trying to gather it.

But the information that I gather in South Dakota is vastly different from what you just stated. If you have ever lived on a reservation, I don't know how anyone can say that a mother—a pregnant woman—has universal access to health care. It is not there.

If you live in a small town outside of McLaughlin, South Dakota, and you are 100 miles away and you have an emergency, whether you are a pregnant woman or a small child, access is not there today.

I don't know about ghettoes, but I would have to assume that the same thing could be said there.

So, I hope you will reevaluate your answer to the question posed by Senator Danforth: Is universal access a fact of life? I would have to say defiantly, in this case, no, it is not. And for you, the expert in the Administration, to come to this committee and, without any exception, say yes, it is—I hope it is inadvertent—but it certainly is misleading as those of us who are making decisions with regard to policy have to evaluate whether the goal stated by Senator Danforth is a valid one or not.

Dr. **Windom**. May I comment? Senator, it does vary, and I want to emphasize that. But I would like to point out that, in the Indian Health Service, which is a very important part of our Public Health Service, we have the lowest infant mortality rate in our country, lower than 9.5 in average per thousand. So, the Indian Health Service has been very effective overall. There may be pockets in the Indian Health Service that are not reached; but overall they have a better birth weight than our Nation as a whole.

Senator **Daschle**. Along that line, and I am not going to challenge that, but I hope you will insert for the record infant mortality found on Indian reservations today. Would you do that?

Dr. **Windom**. I certainly will.

[The information follows:]

NUMBER AND RATE OF INFANT DEATHS, AMERICAN INDIANS AND ALASKA NATIVES, 1983–1985, AND UNITED STATES ALL RACES, 1984

[Infant mortality rate based on infant deaths per 1,000 live births]

	Number of		Infant mortality rate	Ratio: Indian rate to U.S. all races rate
	Infant deaths	Live births		
IHS reservation States, 1983–85 [1]	1,182	120,355	9.8	0.9
IHS service area, 1983–85 [2]	971	86,143	11.3	1.0
Aberdeen	151	7,816	19.3	1.8
Alaska	129	8,061	16.0	1.5
Albuquerque	39	4,214	9.3	0.9
Bemidji	56	4,594	12.2	1.1
Billings	58	4,566	12.7	1.2
California [3]	23	5,191	4.4	0.4
Nashville	29	2,217	13.1	1.2
Navajo	181	16,246	11.1	1.0
Oklahoma City	108	16,067	6.7	0.6
Phoenix	93	8,916	10.4	1.0
Portland	82	6,756	12.1	1.1
Tucson	22	1,499	14.7	1.4
United States all races, 1984	39,580	3,669,141	10.8	

[1] The IHS Reservation State data pertain to all American Indians and Alaska Natives residing in the States in which Federal Indian Reservations or "traditional" Indian lands are located.

[2] The IHS Service Area data pertain to American Indians and Alaska Natives specifically residing in counties containing or bordering Federal Indian Reservation land or "traditional" Indian land.

[3] Data for California should be interpreted with caution since American Indian/Alaska Native race is underreported on death certificates in that State.

Senator **Daschle**. All right. The committee stands in recess. We are in a live quorum, and we will resume just as soon as we have our vote.

[Whereupon, at 11:50 a.m., the hearing was recessed.]

AFTER RECESS

Senator **Chafee**. Why don't we resume and take our next panel? All right. If everybody would please take their seats, and Ms. Brown, if you will lead off?

STATEMENT OF SARAH S. BROWN, M.P.H., STUDY DIRECTOR, INSTITUTE OF MEDICINE/NATIONAL ACADEMY OF SCIENCES, WASHINGTON, DC

Ms. **Brown**. Good morning. My name is Sarah Brown. I am from the Institute of Medicine, and I will speak mainly about prenatal care this morning.

The points I will make derive from two activities conducted by the Institute of Medicine: a report published in 1985 on preventing low birth weight, and a project now nearing completion on how best to draw women into prenatal care early in pregnancy.

The continuing emphasis of the Institute of Medicine and many other groups on prenatal care rests on the broad and deep consensus that it is an effective intervention, strongly and clearly associated with improved pregnancy outcomes and with reduced infant mortality. It also appears to be cost-effective; but despite the proven value of this service, not all women obtain such care while pregnant.

In fact, in 1985 about one-quarter of all pregnant women did not begin prenatal care early in pregnancy, and over five percent received little or no care at all. Of course, for some subgroups—teenagers, minority women, and so forth—the rates are far worse.

And when you look over time at trends, in some areas the picture is getting worse and not better. It is disintegrating and not improving.

Now, why are these utilization rates so poor? Why is it, for example, that in some areas of New York City, over half of all babies are born to women who receive no prenatal supervision at all, or just a few visits close to the time of delivery?

Our Institute committee's findings and conclusions on this matter of barriers to care will be in our forthcoming report; but let me say now that system-based external factors are strikingly prominent in all the data we have reviewed. The evidence is strong that when financing in particular is adequate, when providers to care for low income women are plentiful, and the system is easy to enter, prenatal care use improves significantly. There is really no mystery to it.

And in the question and answer period, I would be happy to take up this issue of women's information and motivation.

Unfortunately, though, our complex maternity programs don't often function well, particularly for poor women. Many programs have been developed in past years to encourage better use of prenatal care and, in some areas, a modest degree of success has been achieved; but along the way, we have also created a very complicated tangle of projects and policies, with probable losses in efficiency manageability, and effectiveness.

Let me highlight three more focused concerns. The first centers on Medicaid. Indisputably, expanding Medicaid to cover increasing numbers of low income pregnant women is a critical first step in improving the use of prenatal care; and in that context, S. 2046 and S. 2122 now under consideration are valuable and important. Their basic thrust is completely consistent with what we have learned about barriers to care.

Expanding eligibility, however, needs to be joined by major administrative reforms in the program to reduce its complexity, to enroll more providers—an issue again I would like to take up in more detail—and in general, to make it a more workable system.

With regard to the application process, for example, reports from the front lines reveal an administrative tangle of immense proportions, an intricate, ever-changing system that is difficult for many case workers, let alone applicants, to understand.

The application process can be demeaning and so time consuming as to almost ensure that pregnant women relying on the program won't begin needed care until many weeks into pregnancy. Reforms are thus needed to shorten and simplify and dignify it, to continue moving it as far away as possible from the welfare environment, and to change a case worker's orientation from "How can I find a way to keep this applicant off Medicaid?" to "How can I welcome her onto the program today?"

A second point concerns private insurance. Whatever criticisms can be leveled against the 54 Medicaid Programs can also be made about the nation's thousands of private health insurance plans.

Recent studies reveal that the presence of private insurance does not ensure that comprehensive prenatal services can be secured, nor does it necessarily protect women from significant financial burdens.

A third point I want to highlight has to do with the content of prenatal care. As you may know, considerable confusion exists about what prenatal care should include, and there is concern that the quality of care is inadequate in some settings.

I mention this content area because, as major purchasers of care, Medicaid and the Maternal and Child Health Block Grant should be deeply concerned about what they are purchasing.

I will conclude by again raising the issue of international comparisons that others have this morning. Many other countries provide care to pregnant women as a form of social investment. They have developed relatively simple, well functioning systems, often with more meager resources to draw on than those available here. Prenatal care, like health services generally, is made readily available with minimal barriers on preconditions in place; and it is closely connected to numerous social and financial supports.

As a result, these countries report that virtually all of their pregnant women begin care early in pregnancy and, not surprisingly, their rates of maternal mortality, infant mortality, and low birth weight are often lower than those here.

This profoundly different concept and experience of maternity care was recently explored at international hearings held by the National Commission to Prevent Infant Mortality. I would urge you all to review the hearing record from that day. It contains a lot of valuable ideas for all of us to consider as we look beyond our current morass of programs. Thank you.

Senator MITCHELL. I just walked in while Ms. Brown was testifying, so I don't know, Dr. Wagner, whether you have testified yet or not.

Dr. WAGNER. No, I haven't.

Senator MITCHELL. All right.

Dr. WAGNER. I would be glad to now.

Senator MITCHELL. We will be pleased to hear from you.

[The prepared statement of Ms. Brown appears in the appendix.]

[Questions and answers of Ms. Brown and Ms. Wagner follow:]

QUESTION FOR MS. BROWN AND MS. WAGNER

Several of our witnesses today have submitted statements indicating that Medicaid enrollment procedures raise significant barriers to obtaining prenatal care. In the 1986 Reconciliation Act, Congress made possible a determination of "presumptive eligibility" for pregnant women to expedite their application for Medicaid coverage. Has this approach been successful? What else could be done to improve access to prenatal care for Medicaid-eligible women?

The presumptive eligibility clause has been adopted by only 12 States to date. Thus, its potential benefits are at present limited. It is important to note, however, that even where presumptive eligibility has been taken up, a "qualified provider" is limited to publicly funded health departments, hospitals, and clinics, but not private physicians' practices. Thus, the presumptive eligibility clause reinforces the tendency to channel Medicaid eligible women into sources of prenatal care that are separate from those used by private patients. Relaxing the definition of "qualified provider" might encourage private physicians to serve Medicaid patients.

Other actions to encourage access to prenatal care for Medicaid-eligible women would be to require a shortened application form for Medicaid-only applicants, and to place Medicaid enrollment personnel in public health clinics or other locations where poor women would be likely to come for pregnancy verification. These changes would not involve extensive "outreach" expenses but could add dignity and ease to the enrollment process.

QUESTION FOR MS. BROWN AND MS. WAGNER

Your statements both illustrate the tremendous medical costs that can be incurred by a very small newborn child.

What are some of the longer term health costs of these low birthweight babies? Who pays when private insurance runs out, especially if Medicaid is not available?

Evidence from a study of neonatal mortality in 1978-79 indicated that for every 1000 low birthweight births (less than 5 lbs, 8 oz), about 150 will have moderate or severe developmental impairments at the end of the first year of life. Some of these children are technology-dependent, and many are developmentally disabled. The costs of treating these children are very high. OTA estimated that every severely impaired low-birthweight survivor generates discounted life-time costs of special health and educational services of $177,000 to $634,000. A moderately impaired child generates life-time costs of $90,000 to $167,000. On average, a low birthweight birth costs the health and special educational system between $14,000 and $30,000 in discounted dollars over the lifetime of the child.

These costs are borne by a combination of parents and their insurance policies, philanthropic organizations, local and State Governments, the Federal government, through Title V Services for Children with Special Health Care Needs, Medicaid, Medicare, and Education for the Handicapped Funds, and the general public through subsidization of uncompensated health care. When a child's health insurance runs out, the other sources of funding must come in. OTA's study of technology-dependent children (a sub-group of the population under discussion) indicated that the availability of funding from the various sources described above varies enormously from State to State and from child to child, depending on his or her particular condition and family circumstances. Public sources of funding are highly variable, and parents often feel overwhelmed by the multiple bureaucracies involved. In some cases, some services may simply not be provided.

QUESTION FOR PANEL OF MS. BROWN AND MS. WAGNER

I have always been most impressed by the arguments that prenatal and infant care are a national investment which pays off in the long term by producing healthy citizens. You have done a good job of illustrating that, without further investments in improving infant mortality, all of society pays the costs in the future. This logic has been a compelling one in Medicaid. Do you think that private insurers and employers approach coverage of children this way?

If so, what approaches do private groups use to improve access to prenatal care?

Under the Pregnancy Discrimination Act of 1978 employers with 15 or more employees who offer group health plans to their employees are required to offer maternity services as they would any other health care benefit. However, employers often include family coverage and coverage of dependents only as a voluntary benefit, and often with a sizeable premium. This discourages employees, particularly low-income employees, from enrolling their dependents in group health insurance. The result is that many pregnant women and children are uninsured. For example, OTA estimated that between 14 and 19 percent of all infants were uninsured in 1986.

Because of employee turnover and enrollment/disenrollment cycles for private insurance, private third party payers do not reap the entire benefit of offering early or more comprehensive prenatal care benefits to their employees. Since they cannot reap the full financial savings associated with early care, they are not as likely to provide such benefits as they would be were all such costs and savings internalized over the course of an employee's lifetime.

QUESTION FOR PANEL OF MS. BROWN AND MS. WAGNER

Your statements highlight what has been one of our most important accomplishments in the past few years, the gradual improvements in Medicaid eligibility for pregnant women and infants. Yet, I think you have both done a good job of reminding members of this Committee that eligibility is only part of the picture.

As I understand it, one piece of the puzzle of improving Medicaid coverage of prenatal care is the unwillingness of some providers to participate in the program. Yet, we have limited resources at both the Federal and State levels and cannot simply increase payment rates across the board. Do you have any recommendations on how provider participation could be encouraged without breaking the bank?

One way to obtain better access to prenatal care for poor women would be to adequately fund Maternal and Child Health Clinics or comprehensive health centers to provide high quality care to women and children in target areas. These clinics or centers could contract with physicians to provide needed care for poor women and children. The contract rates might be lower in the aggregate than those obtained through a broad-based increase in Medicaid fees. Of course, this approach would tend to channel poor women and children into separate providers from private patients, and it would in essence continue to ignore the serious discrepancy between private and Medicaid fees for maternity services. The fact that the real value of funding for primary health care services through Title V, Community Health Centers and Migrant Health Centers has seriously eroded over the past five years suggests that little attention has been given to maintaining previous levels of access for these groups.

STATEMENT OF JUDITH L. WAGNER, PH.D., SENIOR ASSOCIATE, HEALTH PROGRAM, OFFICE OF TECHNOLOGY ASSESSMENT, WASHINGTON, DC

Dr. WAGNER. Thank you, Mr. Chairman. I am Judith Wagner, and I am a Senior Associate at the Office of Technology Assessment and the project director of a recently completed study on children's health.

For the sake of brevity, I would like to submit my prepared remarks for the record and make just a few comments on three issues that we feel are important in children's health care.

The first issue, which you have heard before this morning, has to do with the cost effectiveness of early prenatal care. We looked long and hard at the evidence on prenatal care's effectiveness and, despite some serious shortcomings in the methodologies of most studies of prenatal care, we were able to conclude that earlier or more comprehensive prenatal care can make a difference to low birth weight and infant mortality, especially in poor women and teenagers.

We also found that the medical costs of early care are likely—highly likely—to be outweighed by the health care savings down the road from reducing the need for treating low birth weight babies. We estimated that each low birth weight baby costs the health care system, on average, between $14,000 and $30,000. If Congress wanted to realize net health care savings and at the same time reduce infant mortality one way it could do this would be to expand Medicaid benefits to all pregnant women in poverty.

The success of such a strategy, however, for reducing low birth weight and infant mortality would depend on how many women actually do get earlier care as a result of new Medicaid eligibility. Other barriers to early prenatal care need also to be removed, such as the lengthy and logistically difficult enrollment procedures in many States to which Ms. Brown has just alluded.

The second issue that I would like to go over briefly is the substantial number of children who do not get adequate primary care. OTA found that children without health insurance, most of whom are poor or near poor, do not get all the care that they should; and the disparity between actual and ideal care is greater, the sicker the child.

A few pertinent facts here include, first, that 14 to 19 percent of all American children under 13 years of age had no health insurance in 1986; 61 percent of these children were poor or near poor, and most of these were children in two-parent families.

In 1985, 20 percent of all two-year-olds in the U.S. were not fully immunized against measles despite the overwhelming evidence that childhood immunizations are cost saving to the health care system.

The percent of children in poverty has increased dramatically in the past ten years. In 1978, about 17 percent of all infants were in poor families; in 1986, it was about 22 percent. At the same time that poverty rates grew, real Federal funding for the MCH block grants, the community health centers, and migrant health centers declined by 32 percent.

If Congress wanted to increase poor children's access to primary and preventive care, it could do two things. First, it could expand eligibility for Medicaid to children in poverty; or, alternatively, it could substantially increase direct funding for services for children through the MC and other grant programs.

Finally, I would like to make a few remarks about a small group of children, somewhere in the vicinity of about 10,000 nationally, with such extraordinary medical needs that they represent a group for whom our public and private health insurance system is totally failing. I am referring to technology-dependent children.

These are children who depend on both a medical device and continued skilled nursing care to keep them alive. The ventilator-dependent child is the prototype, but certainly not the only kind of child who falls into this category.

These children's needs for medical care, physical therapy, occupational therapy, psychological therapy, social services, and even respite care for their parents are so great that they simply create a financial burden for their families that, in some cases, is overwhelming.

The three main failures of both private and public health insurance in dealing with these catastrophic illnesses are, first, the failure to cover as benefits all the kinds of care these children need and in the settings that they need them; second, maximum limits on private insurance policies that ultimately leave the child and his family uninsured; and third, the Medicaid requirement in most States that the family spend itself into poverty before the child is eligible for Medicaid, unless that child is institutionalized.

The key to solving the problems laid out above appears to lie in strengthening the ability of State and local agencies to coordinate services for these children. Help can come from the Federal Government through title V for increased direct services and case management, as well as through revisions in Medicaid that allow for individualized approaches to planning and paying for services for these children. Thank you.

Senator MITCHELL. Thank you, Dr. Wagner.

[The prepared statement of Dr. Wagner appears in the appendix.]

Senator MITCHELL. We will now proceed to questions. Senator Chafee?

Senator CHAFEE. Thank you, Mr. Chairman. You have both highlighted the benefits that would come from extended Medicaid, and I agree with that; but we have one problem, and that is the providers in some instances not being willing to participate. By providers, I am talking about physicians, and hospitals also, I suppose, although that is less of a problem. We are talking about physicians, aren't we?

Ms. BROWN. I would like to respond to that. I think this morning we have talked about physicians, but I have been struck by the total absence of discussion of nurse midwives, and other professionals who, at least in other countries, carry the large part of the burden, certainly for prenatal services, and in many instances for delivery care as well.

I am struck continuously in my assessments of programs around the country as to how we have almost systematically avoided using this magnificent resource, particularly for teenagers, for low income women, and for other at-risk groups for whom nurse midwives are uniquely well trained to care.

Senator **Chafee**. Do we have a trained segment of the community who are listed as nurse midwives? Is there such a degree now awarded or such a certificate?

Ms. **Brown**. Oh, absolutely. It is graduate training beyond the R.N. degree. There are, of course, lay midwives, who I think most people agree are insufficiently trained; but graduate trained nurses who have excellent training in perinatal medicine have been shown repeatedly to be excellent providers of care.

Now, again, I am talking about——

Senator **Chafee**. They are not under the Medicaid reimbursement, I presume; there are problems about their being reimbursed. Is that correct?

Ms. **Brown**. I am not fully familiar with that. Maybe Dr. Wagner is, but let me just say this. We don't have a lot of them in this country. I mean, even if we agreed today that, yes, this is what glows in the dark; this is the answer; we have been so single-minded about keeping the system physician based that even if we decided that we should rely more on other providers, there would not be an enormous pool of certified nurse midwives, for example, to draw on.

Obviously, that can be corrected. I just want you to understand that, when we talk about provider availability, the conversation has been uniquely skewed to only one category of providers. And as I mentioned, in European countries nurse midwives and similar well-trained professionals are the front line; they are not sort of the backup or the people we turn to when everybody else falls apart or won't care for the women.

Senator **Chafee**. I suppose they might have a greater affinity with those they are serving, with their clientele, teenage pregnant girls, for example.

Ms. **Brown**. Precisely, and there are data to prove that.

Senator **Chafee**. But they have a problem, too, of liability, don't they?

Ms. **Brown**. Yes. I was talking to a nurse midwife just the other day whose liability insurance was going from $2,500 last year to $7,000 this year. But in comparison to physician liability, of course it is small. On the other hand, their salaries are so low that it represents a large chunk of income.

The liability problem pervades the issue of capacity and provider availability.

Senator **Chafee**. Is one of your recommendations then that we enlarge the use of nurse midwives and include them in the system to a greater degree than presently exists?

Ms. **Brown**. I am not at liberty to say what our forthcoming report is going to recommend. Our past one did say that, though, and it seems to be common sense.

Let me mention one other thing. This issue of providers' availability, here in the District of Columbia, there is excess capacity among obstetricians in the private sector, among physicians willing to care for affluent women. What we are talking about is limited capacity in the systems willing or able to care for low income women. This is not a total capacity deficit, except in rural areas and in some areas where there is simply nobody at all.

But in cities, there are lots of obstetricians, family practitioners, and others. The problem is getting them involved in the issue of indigent care.

Senator CHAFEE. What about the need for case management for low income patients? Could either of you address that?

Dr. WAGNER. I would like to follow up on the nurse midwife issue. Medicaid does pay for nurse midwives if they are licensed in the State—to the extent that they are licensed in the State.

With respect to case management, I think what Sarah is alluding to, and I think what we need to see is an expansion of the availability of services for women at the beginning of their pregnancies, a willingness or a sense that women have that there are places to go and people willing to serve them.

To the extent that case management enhances that availability of services I think it can be useful; but to the extent that case management, as it has been used in some Medicaid programs as a way of containing costs and limiting provider availability, it may not have the kind of access implications that we would like to have for this type of patient.

Senator CHAFEE. Thank you.

Ms. BROWN. Could I make one comment on case management?

Senator CHAFEE. Yes. My problem, Mr. Chairman, is that I have a firm commitment; I have got to go. I am not sure I can be here this afternoon. Are you going to keep going?

Senator MITCHELL. I believe that is the chairman's intention, Senator Chafee.

Senator CHAFEE. I regret that the witnesses have been held up, and I apologize for having to leave. I want to thank both of the witnesses. Go ahead Ms. Brown; you had something to add?

Ms. BROWN. I just wanted to make a brief comment on case management. My observation is that that means a lot of different things to a lot of people.

Senator CHAFEE. It is a well-used term. I am not exactly what it means.

Ms. BROWN. You are right in that assumption, because in fact it means many different things. What I think in practice it suggests is that, when there is a woman who has many problems, many risks, in our complicated system she has to tap into many programs: WIC, food stamps, housing assistance, AFDC, Medicaid, and so forth.

The system is so complex that we need to hire people to help orchestrate that system for the individual clients. Now, that gets called many things: social support, patient advocacy, patient counseling, and so on and so forth.

But what it is directed at is the chaotic system that particularly a low income woman faces when she tries to get what she needs to have a healthy pregnancy, to get care for her infant, and so forth.

As I said, I don't really understand in all settings what that includes, but it is a marker; it is a proxy for the chaos that the women face in trying to get what they need. And of course, it is important.

Senator CHAFEE. Thank you. Thank you, Mr. Chairman.

Senator MITCHELL. Thank you, Senator Chafee. If I could pursue the point you raised, Ms. Brown, about midwives, am I not correct that Medicaid now requires States to include nurse midwife services as reimbursable under their programs?

Ms. BROWN. I believe that is true. What I was responding to was not so much the Medicaid regulations, but what goes on in practice. The tenor of many communities is that the physicians, for various reasons, will not care for certain women; but the system is organized in a way such that they will not let the midwives care for them either.

A lot of hospitals exclude midwives from delivery privileges, and they have brought other pressures to bear, such that the physician-dominated system cannot fold in these other professionals as well. It is really not more complicated than that

Senator MITCHELL. Of course, as you are well aware, our health care system is essentially a private system with limited public programs; and I want to make clear that many share your view. I am not certain that you are proposing a legislative remedy to that, or whether that is a problem that is somewhat broader in scope and requires a national change in social attitudes.

Ms. BROWN. That is correct.

Senator MITCHELL. Yes. In your eloquent description of your meaning of case management and the difficulties that a woman faces, it is true the system is complex. I am also unclear as to whether or not you have a recommendation to change that.

When the President proposed a series of block grant programs to reduce the number of categorical programs, those who are advocates of such programs vehemently opposed the proposal because they saw it as a rather transparent mechanism to reduce funding overall. We periodically reinvent the wheel in our society, and so we go from categorical to broader programs. What do you suggest we do legislatively to deal with the problem you have described?

Ms. BROWN. I think you put your finger on it. You see, there are really two ways of going about this. You can take the current complex of programs and continue working at the margins, which is I think what we have all been doing for a number of years—expanding a little bit here, trying to streamline a small proportion there. But the notion that we could step back and create a more unified, easily accessible, and I would suspect much simpler system, we don't seem to be able to do for obvious reasons.

Senator MITCHELL. You mean a national health system?

Ms. BROWN. Not necessarily.

Senator MITCHELL. We will all be struck by lightning. [Laughter.]

Ms. BROWN. I may lose my job, but I am not going to say that.

Senator MITCHELL. All right.

Ms. BROWN. No, you see, I think if the political will were strong to take a serious look—a serious examination—of the current programs for pregnancy and infancy and children, I think that over time some suggestions could be made to put something together that perhaps contained elements of what we have and perhaps some new things.

This midwife issue is just one small example of the kind of a perspective that we might fold into a new system, were we designing it.

I don't think it is an imponderable problem, though. I think over time we could think of a way to bring a lot of these programs together, but it would take, as I said, political will. I think in the current environment, that is not present; and what we are doing, as I mentioned a moment ago, is to continue working at the edges and making those changes we are able to.

Senator **MITCHELL**. I have to respectfully disagree. There can't be political will unless there is knowledge and a specific proposal. We invite you here, and we are grateful for your presence and testimony.

One of the reasons we invite you is to point out problems, which you have done very well. The other is to ask you to suggest solutions, which I must say, in all candor, you haven't done well until now. And I want to give you a chance to correct that.

Will you organize your thoughts in writing and provide them to the committee? What specifically do you suggest that we do to deal with the problem which you have eloquently described and which we understand exists? We want to deal with it and we want to demonstrate that we have the political will to do it.

Ms. **BROWN**. Let me say that, with regard to the issue of low birth weight, our group in 1985 in fact did make a number of suggestions which we have presented to the Congress on numerous occasions; and we can do that again.

Our forthcoming report will make some additional suggestions, but we were not asked in our current work to redesign maternal and infant health systems for the United States. The point I want to make is that I think it is possible to do that over time and with a broadly representative thoughtful group. I think the specifics could be worked out, combining private and public sectors and, as I said, drawing on certain elements of the present system

Senator **MITCHELL**. If I, as Chairman of the Health Subcommittee, asked your Institute to do that, would you then do it?

Ms. **BROWN**. Probably.

Senator **MITCHELL**. All right. That will be done, will it not? [Laughter.]

Thank you very much. We really appreciate your testimony.

We will now proceed to the next panel, which includes Dr. Gail Wilensky, Vice President, Division of Health Affairs of Project Hope, Washington, DC, and Paul Newacheck, Assistant Adjunct Professor, Health Policy, Institute for Health Policy Studies of the School of Medicine, University of California at San Francisco, San Francisco, California.

Good afternoon, Dr. Wilensky and Mr. Newacheck. We welcome you, and we look forward to hearing from you. We will begin with you, Dr. Wilensky.

STATEMENT OF GAIL R. WILENSKY, PH.D., VICE PRESIDENT, DIVISION OF HEALTH AFFAIRS, PROJECT HOPE, WASHINGTON, DC

Dr. **WILENSKY**. Thank you for inviting me, Mr. Chairman, to testify before the Health Subcommittee. As you have indicated, my name is Gail Wilensky; I am a Vice President of Health Affairs for Project Hope.

I am here, however, as an independent health policy analyst and not specifically as a representative of Project Hope. The purpose of my presentation is to discuss health insurance coverage and health care spending by families of children with chronic diseases and high-cost illnesses.

In many ways, the problems of these families are similar to other families who are uninsured or underinsured or who are impacted by catastrophic illnesses or who have an adult—usually an elderly person—who needs long-term care.

There are, however, some very important differences for these families, specifically, the number of years that they may face high expenses, the number of family members who may be burdened by having a chronically ill child, the special educational needs for the children, and the particular problems that these families face when the child becomes a young adult and may no longer qualify either for the parent's private insurance or for public programs.

It is also particularly important as we struggle to come to closure on acute care, catastrophic coverage for the elderly and intensify our discussions on long-term care needs which I know you have been very interested in, Senator Mitchell, that we not forget this other most vulnerable aspect of our society—that is the children.

Defining what we mean about who we are concerned about requires some discussion, and I would like to just quickly indicate who it is that I am thinking about and what it is that I mean when I use these terms. There is more information about this in my testimony.

I believe it is most useful to think about the problems of families with children with chronic or high-cost illnesses in terms of the expenditures that they face, rather than whether or not they have a particular disease. I also believe that we must acknowledge the period of time over which this expense is incurred because what a family may be able to tolerate if it only occurs in one year may be very different from what it can tolerate if it is expenditures that must be faced for five, ten, fifteen years, or a lifetime.

And finally, we need to look at the expenditures that the family incurs relative to the family's income.

It is also unfortunately a problem that data for this group is very hard to come by. It is almost always difficult to obtain timely data in the health care area, as I know you have heard before, but it is particularly a problem here because high-cost illnesses in children are fortunately very rare events and because most of our surveys only include information at best on direct medical care expenses and frequently exclude the other social support service costs that go with these children.

We believe that there are about two million children in the United States that have a substantial limitation in their activities and about 225,000 that are severely limited. The characteristics of these children exacerbate their problems in that they are likely to live in low income families—more likely than the rest of society—they are more likely to live in households that are headed by women, and they are more likely to be covered by Medicaid when they are insured rather than private insurance coverage.

The estimates indicate that the expenditures on these children vary substantially. I believe Paul Newacheck will discuss this in some greater detail.

In 1982, these expenditures varied between $870 and $10,000 per year for hospital and physician services only, not counting any other medical or social services. These expenses are between three and 38 times greater than other children incur. The number of physician visits will depend on how sick they are; whereas for most children we are talking about four physician visits a year, for those with the greatest limitations, we are talking about some 22 visits a year.

They are also four times more likely to be hospitalized than disabled children and, once hospitalized, have an average length of stay twice that of children without disabilities.

Using some data from 1980, Paul Newacheck has indicated that these estimates have increased to about $1,200 per child that is disabled; and, as in all medical care, expenditures are very concentrated, that is, some children—even in this group—use a lot more expenditures than the group as a whole. And that is a particular problem.

There is also a problem with neonates. About 150,000 to 200,000 infants are treated annually in neonatal intensive care units, about half of whom are low birth weight infants. Their costs vary dramatically on average from $12,000 to $39,000; but for the very littlest, those who are under 750 grams, they can be as much as $60,000 to $150,000.

And for those that survive, some of them will be normal; others will become chronically ill and dependent for the rest of their lives.

In general, disabled children are more likely to be insured than children as a whole. They also, however, as I have indicated, are more likely to be on Medicaid than they are on private insurance.

There have been some changes that have occurred in the 1980's that have made it particularly difficult for those children with private insurance. Some of the difficulties have occurred because coverage has declined and some because deductibles and copayments have increased. But there have been some beneficial changes as well, such as stop loss provisions and the introduction of case management as a more common part of insurance.

Let me say in concluding that many of the policy responses appropriate for the chronically ill are the same as those for the uninsured and those with catastrophic illness. That means more employment related insurance for the workers who do not now have it, especially insurance with catastrophic coverage; a Medicaid floor and an expanded Medicaid program but particularly, a floor below which we will not allow States to go; and subsidized risk pools for the medically uninsurable.

Targeted service programs, such as the State crippled children's programs, will continue to be important; but the changes that I have just outlined—and I will be glad to discuss them in detail with you during the discussion period are ones that we need to consider more thoroughly.

They are issues we have heard discussed before concerning the problems of the uninsured and the elderly catastrophic. They are particularly important for this group as well.

Senator Mitchell. Thank you very much, Dr. Wilensky. Mr. Newacheck?

[The prepared statement of Dr. Wilensky appears in the appendix.]

[Questions and answers of Dr. Wilensky and Mr. Newacheck follow:]

QUESTION FOR PANEL OF ACADEMICS (Dr. Wilensky & Mr. Newchek)

I am particularly struck by the evidence in your statements that high-cost illness and its financial risks are very unevenly distributed. As I understand it, the evidence is that a very few children account for a disproportionate share of hospital use among children. Is it accurate to say that, in general, most children with severe acute health care needs require hospital care at some point--and is this more true than for adults?

Who pays for this care when the child has no public or private insurance?

Are there less costly alternatives to inpatient care? What should the Federal role be in encouraging the use of less costly services?

Question: I am particularly struck by the evidence in your statements that high-cost illness and its financial risks are very unevenly distributed. As I understand it, the evidence is that a very few children account for a disproportionate share of hospital use among children. Is it accurate to say that, in general, most children with severe acute health care needs require hospital care at some point--and is this more true than for adults?

Answer: It is true that high cost illness and the financial risks attendant to such illnesses are unevenly distributed among children.[1] Children are rarely hospitalized, but most children with high medical care expenses have spent some time in the hospital. Data from the National Health Interview Survey indicate that fewer than 5 percent of children under 18 years old were hospitalized* in 1986.[2] Yet data from the most recent available national survey on medical care expenditures, the 1980 National Medical Care Utilization and Expenditure Survey, indicate that average medical care expenses for hospitalized children under 18 years were nearly 13 times higher than those for nonhospitalized children.[3]

A relatively small segment of hospitalized children with either multiple admissions or lengthy stays account for a disproportionate share of all hospital use among children. For example, 5 percent of children hospitalized in 1986 spent 30 or more days in the hospital. This relatively small group, numbering approximately 120 thousand, accounted for 7.4 million hospital days or 42 percent of all hospital days* for children under 18 years.[4] It follows that policies addressing high cost illnesses should focus on hospital use, especially among children with multiple and lengthy hospitalizations. Children with severe chronic illnesses are disproportionately represented among those with lengthy hospital episodes.

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* excluding stays for well newborn infants

Whether children with severe acute or chronic illnesses require hospitalization is dependent on the nature of their conditions and the adequacy and availability of services provided outside the hospital setting. Certainly, children who are victims of accidents, violence, or other forms of trauma are prime candidates for hospitalization, as are newborns of low birthweight. In other cases, particularly for children with chronic illnesses, proper case management and access to community and home-based services can reduce the need for hospitalization.

Question: Who pays for this care when the child has no public or private insurance?

Answer: Fortunately, 85 percent of children under 18 have some form of health insurance,[5] and both public and private insurance tend to provide extensive coverage of inpatient hospital expenses. Data from the National Medical Care Utilization and Expenditure Survey, for example, indicate that families paid an average of only 11 percent of their children's hospital expenses directly out-of-pocket in 1980.[3] By comparison, that same year families paid an average of 38 percent of physician bills directly out-of-pocket.[3] The relatively generous coverage of inpatient hospital expenses helps to reduce financial burdens for families with insurance, but also creates a financial incentive for patients and providers to use hospital services in lieu of potentially less expensive, but less well covered community and home-based services.

Families of children admitted to a hospital with no private or public health insurance are expected to pay for their accumulated charges directly out-of-pocket. For large bills, hospitals often arrange for payments to be spread over the course of a year or longer. Hospitals have a great incentive to qualify children from indigent families for Medicaid or other public programs. In fact, hospitalized children were almost twice as likely to be covered by Medicaid as nonhospitalized children in 1986.[5] Because hospital charges are very high, many children from low income families will quickly become eligible for

Medicaid by spending down to state-set financial eligibility levels in those states with Medically Needy programs (about two-thirds of all states). In the remaining states it is more difficult to qualify for Medicaid, and the accumulated charges may be "written off" as bad debts or subsidized through charitable organizations. Despite limited budgets, Federally and State funded Title V programs also help meet hospital care bills for chronically ill and other low income children with inadequate health insurance. Finally, children without insurance are often transferred to county or other public institutions and, indirectly, become subsidized through public funds.

Question: Are there less costly alternatives to inpatient care? What should the Federal role be in encouraging the use of less costly services?

Answer: Approximately two-thirds of all hospital admissions are for acute health problems.[6] Once treated these children often require little additional care. The remaining children are hospitalized for chronic illnesses and typically have ongoing care needs. Policies to reduce hospitalization for children with acute health problems will generally differ from those aimed at reducing hospital stays for chronically ill children.

Reducing hospitalizations for children with acute illnesses might best be accomplished through prevention programs. Such programs might include those aimed at reducing accidents, violence, substance abuse, and other avoidable traumatic events. In addition, prevention in the form of improved access to primary care services can lead to early identification and amelioration of health problems that would otherwise lead to hospitalization. Programs such as Early and Periodic Screening , Diagnosis and Treatment (EPSDT) under Medicaid are ideally suited for this purpose, but only half of all poor children receive Medicaid and only a fraction of Medicaid recipients actually obtain ESPDT services.[7,8] Finally, other prevention programs could be pursued to reduce the need for the most expensive form of hospitalization--neonatal intensive care. A growing body of evidence supports the notion that quality prenatal care reduces the likelihood of low birthweight and the need for intensive hospital care.[9] Those pregnant women least likely to obtain timely prenatal services are disproportionately poor and near-poor. Recently enacted legislation permitting states to cover pregnant women up to 185 percent of the poverty level should help in this regard, but since the program is optional it is unclear how many states will adopt more generous eligibility standards. Another approach to be considered is mandating coverage of low income pregnant women under Medicaid *and* mandating provision of an adequate package of prenatal care benefits for eligible pregnant women.

Policies to reduce hospitalization for chronically ill children must recognize the ongoing nature of their need for health services. Chronically ill children with some level of long-term limitation in their activities spend an average of six times as many days hospitalized as other children. Children who are unable to attend school or engage in ordinary play due to chronic illnesses spend 40 times as many days hospitalized as nondisabled children.[10] In recent years third party payors, both private and public, have increasingly considered alternatives to hospital care for severely chronically ill children (e.g., ventilator assisted children). These community and home-based alternatives appear promising from the viewpoint of third party payors. However, financial savings from home care often result from a shift in the burden of care from paid hospital nursing staff to unpaid family members.[11] Hence, it is important to consider whether home care creates an excessive care-giving burden for family members. At minimum home care programs for chronically ill children should include a comprehensive set of medical and social services, including case management, for the child and provision of respite and counseling services for family care-givers. There are additional concerns about the safety and efficacy of home care for chronically ill children. Although not all the evidence is in yet, initial results appear promising in this regard. One study in Montreal demonstrated that home care for children with complex medical conditions such as hemophilia and asthma is quite safe.[12] In the U.S., an 80 percent reduction in hospital use and a 70 percent reduction in days lost from school or work has been demonstrated for participants in the Hemophilia Diagnostic and Treatment Centers.[13] These comprehensive care programs combine home care with care provided at regional centers. Another study in New York demonstrated that home care provides measurable psychological and social benefits for the child and mother, and results in more satisfaction with care.[12]

It would seem prudent for the Federal government to encourage the gradual development of home care and community-based alternatives for severely ill children. Development of alternatives should proceed gradually to ensure that home care programs are comprehensive in scope, provide needed services in a safe and medically efficacious manner, and do not place undue burdens on the family. The Bureau of Maternal and Child Health and Resources Development has funded several demonstration projects relating to home care and many lessons could be drawn from these projects. The American Academy of Pediatrics has prepared general guidelines for home care that might help to serve as a beginning basis for federal legislation concerning the quality and adequacy of home care services for severely ill children.[14,15] Additional guidelines are being developed by the Academy of Pediatrics for the Health Care Financing Administration.

Much of the public debate over home care for severely ill children has focussed on the costs of home care compared to hospital-based care. While cost issues are clearly important, issues of quality of life for severely ill children and their families are often neglected in these discussions. Any guidelines adopted for public and privately financed home care programs should balance the medical and social needs of the child and the family with the costs of care in alternative care settings.

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STATEMENT OF PAUL W. NEWACHECK, M.P.P., ASSISTANT ADJUNCT PROFESSOR, HEALTH POLICY, INSTITUTE FOR HEALTH POLICY STUDIES, SCHOOL OF MEDICINE, UNIVERSITY OF CALIFORNIA, AT SAN FRANCISCO, SAN FRANCISCO, CA

Mr. NEWACHECK. Mr. Chairman, I am pleased to appear before you today to discuss the health care needs of chronically ill and disabled children. For the last five years, I have engaged in research concerning the health care use and expenditures for this population. Based on that research, I would like to call your attention to just a few key points from my written testimony.

First, chronic illness varies in its impact on children's health and functional status. While many children have mild chronic conditions, only about five percent of U.S. children under age 18 suffer some degree of disability or limitation in their activity due to chronic illness. This represents currently about three million children nationwide.

These children range from those who are limited in sports and other recreational pursuits to those who are unable to attend school or to engage at all in ordinary play with other children. So, what we have is a spectrum or a continuum of chronic illness ranging from the very mild to the very severe. For the remainder of my testimony I would like to focus on the five percent of U.S. children with some level of disability.

These disabled children need and use many more health services than nondisabled children. They use six times as many hospital services, three times as many physician services, and six times as many other health professional services.

These higher use levels translate directly into higher charges and out-of-pocket expenses. In addition, expenditures for this population are unevenly distributed within the disabled population. A relatively small proportion of disabled children accounts for the majority of total charges and out-of-pocket expenses.

Consequently, families are unevenly exposed to the financial risks associated with chronic illness. While most disabled children have some form of private or public coverage, one in every seven disabled children is uninsured. This translates to nearly a half million disabled children without any form of health insurance. Many more have coverage that provides inadequate financial protection.

Higher income families tend to be better insured and appear to be more capable of meeting health care expenses not covered by insurance. Moderate and low income families, however, are much more likely to be uninsured or underinsured and have less financial resources to draw upon in meeting health care bills not covered by insurance.

Disabled children from families below the poverty level, for example, are twice as likely to be uninsured as their counterparts in families with incomes above the poverty level.

Adequate health insurance or other mechanisms for paying for care should be available to families of all disabled children. The current patchwork of private and public programs falls short of reaching this goal.

Private health insurance, while adequate for meeting many disabled children's needs, often provides only limited coverage for home health and other services needed by severely disabled children.

Medicaid plays an important role in financing the health care needs of low income disabled children. However, income eligibility thresholds are often quite low and vary considerably from State to State. Recent survey data indicate that only six out of every 10 disabled children below poverty are covered by Medicaid.

Families may also turn to the Federally and State financed programs for children with special health care needs, formerly known as Crippled Children's Service Programs. These programs offer case management and other critical health services to disabled children; but like Medicaid, eligibility criteria for access to health care services varies from State to State.

The result is that a disabled child may be ineligible for either program in one State but eligible for both in another. These inequities in the current system suggest that new initiatives are needed if we are to truly meet the health care needs of disabled children and protect their families against undue financial burden.

Our Nation's children and our society deserve no less. Thank you.

Senator MITCHELL. Thank you very much, Mr. Newacheck.

[The prepared statement of Mr. Newacheck appears in the appendix.]

Senator MITCHELL. Dr. Wilensky, in your closing remark, you made a series of recommendations, one of which was what you described as a Medicaid floor.

Dr. WILENSKY. Right.

Senator MITCHELL. Would you provide me with more detail on that, please?

Dr. WILENSKY. Yes. The concept is that, under our present system, there is no level below which we will not allow States to go; and the State level of income eligibility as I know you know, varies according to the AFDC eligibility level in that State.

One of the changes—and not only for this group, but for the problems that we have among the poor uninsured in general, but obviously particularly for this group of people who will be high users and are especially vulnerable—is to establish a floor, some percentage of the poverty line—60 or 70 percent; whatever the Federal Government believes that it is both willing to finance and willing to impose on the States—below which we would not allow States to go.

That would at least set some limit, not tied to AFDC; I heard and have heard before the concept that, if the State must also bring in AFDC, that will even make it less likely for States to do that, but some floor below which we will not allow States to go in Medicaid eligibility.

Senator MITCHELL. The specific question I raised earlier with Governor Mabus was legislation which has already been introduced, which would mandate States to provide maternal care coverage for women and families up to the Federal poverty level. Is that the kind of thing you are talking about?

Dr. WILENSKY. Yes, exactly.

Senator MITCHELL. All right. Thank you both very much for your testimony. We appreciate it.

Senator **Rockefeller**. Thank you both very much. If each of you could move off to the side at the witness table, I could bring up the next two witnesses. Do you have to go?

Dr. **Wilensky**. In about five minutes.

Senator **Rockefeller**. Then you had probably better. All right. Thank you very much. Mr. Douglas Peters, Senior Vice President, Representation and Public Affairs, Blue Cross and Blue Shield Association, Washington, DC, and Arthur Lifson, Vice President, Equicor, Inc., testifying on behalf of Health Insurance Association of America, New York, New York.

Gentlemen, we apologize for this odd process called "hearings." It must be bewildering to any sane citizen, but we are grateful that you are here and are interested in what you have to say.

STATEMENT OF DOUGLAS S. PETERS, SENIOR VICE PRESIDENT, REPRESENTATION AND PUBLIC AFFAIRS, BLUE CROSS AND BLUE SHIELD ASSOCIATION, WASHINGTON, DC

Mr. **Peters**. Senator Rockefeller, I am Doug Peters, Senior Vice President of Blue Cross and Blue Shield Association. Our organization does appreciate the opportunity to testify.

I intend to briefly review Blue Cross and Blue Shield plan insurance practices regarding children, and second, to outline some of our programs where plans have been developed specifically for children. And finally, I will offer a few recommendations.

Our plans currently cover approximately 16 million families, including 21 million children, usually through employer-sponsored programs. Typically, newborn children are covered at birth and are added to the policy regardless of the child's medical condition.

Policies that do not specifically include dependent coverage provide insurance protection for newborns for a specified period of time, usually 30 days, during which time family coverage can be purchased.

One of the key problems affecting children is the lack of dependent coverage through the employer-sponsored group. In a recent survey of our small employer group markets, those with 25 or fewer employees, only half of the small group employers contribute at all to dependent coverage.

Seventy percent of our plans report that the coverage most commonly purchased by small groups includes coverage for routine, prenatal care. Over one-third report well baby care being covered as well.

Such coverage is more likely to be provided by large employer groups who tend to offer more comprehensive benefits to their employees.

Our small group products typically include a lifetime maximum of $1 million, although some small group products include no such lifetime maximum.

In reviewing the benefits offered by Blue Cross and Blue Shield plans, it is worth noting a relatively new program, Individual Case Management. You have heard comments and references to it previously today.

From our perspective, this program can result in children and others receiving special benefits that may not be normally covered under their policy. For example, if a child's coverage did not include home care services, but the case manager recommended home care as an alternative to hospitalization, those services could be covered within the context of the policy.

Today, all of our plans offer a home care benefit; 70 percent of our plans have case management programs.

Many Blue Cross and Blue Shield plans have developed new and innovative arrangements for low income children. In 1985, Blue Cross of Western Pennsylvania and Pennsylvania Blue Shield created the Caring Program for Children. The program offers primary health care to children not eligible for Medicaid, but whose parents cannot afford health insurance.

Nearly 8,000 children have received primary, preventive, and emergency health care services at no cost to their families. The program operates through contributions of $13 a month from foundations, businesses, unions, individuals, and church groups. They sponsor the children regardless of their medical condition.

The Blue Cross plan matches every contribution, dollar for dollar, and subsidizes the administrative cost. This, in effect, enables two children to be enrolled for every one sponsored by a public contribution.

Other Blue Cross and Blue Shield plans have developed similar programs, including plans in Missouri, Maryland, Alabama and North Carolina. The Blue Cross plan has received a grant from HHS for health education, prevention, and awareness and to extend this program to other Blue Cross and Blue Shield plans across the country.

Another initiative of note—I believe referenced earlier by Senator Baucus—is that Blue Cross and Blue Shield plans recently joined forces with the March of Dimes and radio and television companies to reduce infant mortality and morbidity. The "Beautiful Babies Program," sponsored by Blue Cross and Blue Shield of the National Capitol Area and a similar program sponsored by Blue Cross and Blue Shield of Utah, rely on extensive public education to encourage pregnant women to visit their doctors

One of the most important outcomes of the program is to identify high-risk pregnancies as soon as possible.

We have other innovative programs to increase access of care for children, referenced in our written testimony and in material that has been made available to you.

In the context of reaching all the children, a public and private effort, we feel, is essential. In that context, we have a few recommendations for your consideration.

First, we believe that the Congress should consider requiring States to cover pregnant women under Medicaid and to phase in coverage of children up to the poverty level. In addition, for lower income workers, we believe that some form of a Medicaid buy-in should be considered for employees and dependents.

We believe that Congress should provide the same 100 percent tax deduction for health benefit expenses to unincorporated businesses, sole proprietorships, self-employed and individuals, as currently permitted for corporations.

Finally, we are concerned that mandating inclusion of catastrophic benefits in all health insurance products might result in the erosion of employer financial support for dependent coverage; and we would, therefore, respectfully suggest a very careful assessment of this approach as this committee evaluates options and alternatives.

We strongly support Federal efforts to expand benefits to those we cannot reach, and we look forward to working with the committee as it begins to develop its legislative strategy. Thank you.

Senator ROCKEFELLER. Thank you, Mr. Peters. Thank you very much. Mr. Lifson?

[The prepared statement of Mr. Peters appears in the appendix.]

[Questions and answers of Mr. Peters and Mr. Lifson follow:]

Blue Cross
and
Blue Shield
Association

Questions for Panel of Insurers (Mr. Peters and Mr. Lifson):

Question #1. Insuring Children

I am most interested in Mr. Peters' description of the "Caring" program, under which several Blue Cross plans have worked with business, civic and religious organizations to subsidize insurance coverage for children who have neither public nor private insurance. As I understand it, these plans cover primary preventive and emergency health services at no cost to the family.

While I understand that the potential for such plans is necessarily limited, I wonder whether any consideration has been given to offering a commercial product which would cover children only, for a limited set of services. Even parents in uninsured families might be willing to purchase such coverage were the costs reasonable. For example, it has been suggested that such a product be marketed through the school systems.

Answer: (Mr. Peters)

The Blue Cross and Blue Shield Plans involved in the Caring Program for Children are considering two approaches to making regular dependent-only coverage available at reasonable cost.

The first approach would be to simply expand eligibility for the Caring Program to higher income parents, for example to include parents with incomes up to two times the federal poverty level.

The second approach would be to redesign the rating structure for nongroup benefit packages to take into account the lower risk that younger subscribers represent. For example, where currently the rate tables might place all persons under age 30 into one bracket, the tables could be revised to make 4 age-related brackets: 0-6 years, 7-12 years, 13-18 years, and 19-29 years. This would result in lower premiums for younger subscribers and higher premiums for older ones. The negative to this is that it would increase rates for the older subscribers because the better risks would be moved into another pool.

Question #2. Case Management

Both of you included in your testimony a discussion of case management for children with severe and chronic health problems.

How does case management work, for example, in the case of a parent who has a child with a chronic condition but does not know where to begin to seek the right services for that child?

Answer: (Mr. Peters)

Individual case management is an organized effort to identify patients that have the potential to be high-cost, long-stay, and/or complicated discharge planning cases, as early as possible, and to manage their health care benefits as cost effectively as possible. This may include the provision of benefits not originally included in the contract.

The Plan will identify a potential patient through internal review methods such as preadmission review, concurrent review, or claims review. Referral from outside sources such as hospital discharge planners, physicians, employers, or patient/family is also used. Participation in a case management program is always voluntary and if a patient does not want to participate he/she will continue to receive his/her regular hospital benefits. Once the patient is identified the case manager will contact the hospital and the physician to determine if the patient can receive services in an alternative setting. The case manager will also assess whether the patient needs additional services to move to the alternative setting (e.g., a utilization ramp built at home) and whether the transfer to an alternative setting is cost effective. If this is possible the case manager will communicate with the patient/family to determine if they are willing to participate in the case management program. If all relevant parties concur, the transfer will be arranged and benefits will be provided for services in the alternative setting. In some cases the employer will need to approve case management benefits especially if they are extracontractual.

The case manager will monitor the patient in the alternative setting on an ongoing basis to determine if the patient is still in need of skilled services and also to determine if the patient is receiving the services that were approved. This monitoring can be on-site, by telephone, or through medical records.

The underlying criteria in a case management program are that the patient is receiving services in an alternative setting in lieu of hospital care and these services are cost effective. Therefore, once the patient is assessed to no longer need skilled services, case management benefits will be terminated. In some cases the case manager will assist the patient/family in identifying additional funding sources when necessary.

Question #2b: Case Management

Is case management designed to improve access to special care that these children may require, or is it really more of a cost control system designed to channel these children to low cost providers?

Answer: (Mr. Peters)

An individual's case management program is always established by using the treatment plan from the patient's attending physician. Case management programs provide patients with the possibility of receiving benefits that were not part of their contract benefits and/or the help of the Plan in guiding a patient through the system. In this sense case management definitely improves access. For example, a ventilator dependent child may have hospital benefits to cover this care as an inpatient but may have limited or no home care benefits. With a case management program, the Plan can arrange for the child to be cared for at home and to receive benefits that may not have been available. Since the program is voluntary the Plan never forces the patient into case management.

Question 2c: Case Management

How much freedom of choice do these parents have to select providers?

Answer: (Mr. Peters)

Many Plans have contractual arrangements with providers to provide services at a preferred rate. The Plan will encourage the parent to use these providers. However, in most cases the Plan will give the patient/family a choice rather than dictating which provider to use. If the parents prefer to use a provider that is not preferred, the Plan will usually approve this choice unless the rates charged are so high that the transfer no longer is cost effective. In this case the Plan may work out some type of co-payment if the parents insist on this provider.

In addition, the patient treatment plan used in case management comes from the patient's attending physician. The providers used will also have to be approved by the physician before any choice is made.

Question #2 Follow-up: Case Management

If an individual with a chronically ill child had no health insurance, are there public or private networks for channeling these children to appropriate providers (similar to your case management programs)? Specifically, do you think that case management for these children would be an appropriate requirement under the Medicaid program?

Answer: (Mr. Peters)

A case management program can be used with any insured group, however, each type of insured group may be unique and require different approaches. Although the Medicaid program has unique rules and regulations, we believe it is feasible for the states to establish case management programs as a cost effective approach to providing health care. A number of states are infact demonstrating case management in their medical programs, with early results being favorable. For example, the cost of care for a ventilator dependent child could be greatly reduced by providing benefits for home ventilator care. Another example where case management can be used cost effectively is with AIDS patients. If an AIDS patient does not have private insurance he (the patient) will probably receive care as an inpatient. However, if an exception is made to cover home care, the patient can receive benefits at home, at presumably reduced overall costs. In addition, the case manager may be able to arrange for free services from community groups. A case management program will also provide the services of the case manager to help the patient through the maze of health services and to receive cost effective and quality care.

Question #3 Lifetime Maximums

Mr. Lifson's statement indicates that an increasing number of plans have increased or eliminated lifetime maximum benefit limitations. I assume that relatively few of the children covered by your plans exceed these maximums. How expensive is it for the employer and/or employee purchasing the plan to eliminate these maximums altogether, especially for dependents?

Answer: (Mr. Peters)

It is impossible to provide a dollar figure in response to this general question, because in each specific instance the cost would depend upon the benefits provided by the plan and its existing lifetime limit. Generally, it is very inexpensive to move from a one million dollar limit to unlimited benefits. It would be far more expensive to move from a fifty thousand dollar limit to a million dollar limit because the probability of incurring costs in excess of that lower figure is, comparatively, much greater.

STATEMENT OF ARTHUR LIFSON, VICE PRESIDENT, EQUICOR, INC., TESTIFYING ON BEHALF OF THE HEALTH INSURANCE ASSOCIATION OF AMERICA, NEW YORK, NY

Mr. **Lifson**. Thank you, Mr. Chairman. Mr. Chairman, children are close to everyone's heart. They are the future of our society. Like the population as a whole, most children have excellent protection against the high cost of medical care. About 70 percent are covered by private plans; 15 percent by public plans, primarily Medicaid.

The vast majority, about 85 percent, of the children covered by private plans are covered under employer group plans, and 15 percent by individually underwritten plans sponsored by insurance companies, Blue Cross plans, and HMOs.

Senator **Rockefeller**. Could you say again what percentage of those are covered by employer plans?

Mr. **Lifson**. Eighty-five percent, we believe, of the children who are covered under private plans are covered under employer-sponsored plans.

Senator **Rockefeller**. And those 85 percent represent about what percentage of all children?

Mr. **Lifson**. You have to take 85 percent of 70 percent; an somebody has to calculate it. That represents approximately 60 percent—about 55 to 60 percent—of all children.

Senator **Rockefeller**. Thank you.

Mr. **Lifson**. Maximum benefit levels have typically been raised to $1 million or more with limits on out-of-pocket expenses. For about 80 percent of all plans, those out of pocket limits are $2,000.00 or less.

One of the recent developments that has made it possible for insurance companies to provide such expanded benefits, while controlling the expense of the benefits, has been the development of case management services.

Under a case management approach, an insurer working with the insured, the family, and the family's physician, designs and implements a plan for the care of the individual.

The care plan often includes items of service not covered under the plan but necessary to assure high quality and economical care. These services are paid when part of an improved case management plan.

For example, my own company routinely provides for travel and hotel expenses for a family member when we suggest a burn center far from the insured's home town. This approach is used with relatively low frequency, high-expense conditions.

For children the diagnoses that might trigger case management services under private plans could include cystic fibrosis, cerebral palsy, spinobifida, heart, respiratory and GI anomalies, fetal malnutrition, and near drownings, in addition to high-risk infants.

There are other diagnoses such as head and spinal cord injuries, which have a high proportion of older primarily adolescent children associated with them.

In order to give you an idea of the involvement of case management, in the care of the chronically ill or injured children, for Equicor—my own company—about 50 percent of the head injury cases and 25 percent of the spinal cord injuries were dependent children. Also, for my own company, about 1,000 high-risk infants are referred per year for case management; and 34 percent of them will be chronically ill.

For the year 1987, Equicor had some 2,500 case management referrals; 23 percent were dependent children. Of the 893 cases that were openly managed, 250—28 percent—were dependent children. We believe case management not only assures the individual high quality care, but also economical care.

The chronically ill injured child managed by Equicor at an average expense of some $40,000, as opposed to estimated expenses without case management of $90,000—a per case savings of $50,000.

Mr. Chairman, while all this is excellent for those who have insurance, we are deeply concerned about those 35 million Americans who have no health insurance—public or private—one-third of whom are children.

We have a series of specific legislative proposals that we believe will significantly reduce the problem of the uninsured.

First, give self-employed individuals 100 percent tax deductibility for their health insurance as long as they cover their employees and their dependents.

Second, extend the existing preemption of State mandated benefits currently enjoyed by self-insured employer plans to insured plans so that insurers can offer affordable plans to small employers.

Third, adopt properly crafted legislation guaranteeing State pools for uninsurables in all the States.

Fourth, all Americans below the poverty line should be covered under Medicaid. Approximately one-third of all uninsured Americans are officially in poverty.

Certainly, as a minimum, children below the poverty level should be covered under Medicaid, regardless of family relationships or the work status of adult family members.

Currently, there are some 4.3 million uninsured children below poverty, about 12 percent of the total uninsured population.

We also support enactment of medically needy, Medicaid spend-down programs in all of the States.

In closing, Mr. Chairman, we specifically want to commend Senator Bradley and the other members of this committee on both sides of the aisle for sponsoring S. 2122, the Medicaid Infant Mortality Amendment, which we wholeheartedly support and endorse. Thank you.

Senator ROCKEFELLER. Thank you, Mr. Lifson.

[The prepared statement of Mr. Lifson appears in the appendix.]

Senator ROCKEFELLER. I thank both of you, for coming forth with very clear suggestions as to what ought to be done by both the public and the private sector. I would say that Blue Cross and Blue Shield has a tradition of doing that in this committee, and that is very important.

I was saying earlier to the Administration witnesses that they were proposing what we should be thinking about. You are actually proposing what ought to be done—both of you—and that is important and encouraging as we try to grapple with this.

I will just ask a couple of questions, and then there will be more that will be submitted to you. I hope that is not inconvenient for you. We would appreciate it if you would answer the written questions.

Mr. **Lifson**. Certainly.

[The questions appear in the appendix.]

[Questions and answers of Mr. Peters and Mr. Lifson follow:]

QUESTION FOR PANEL OF INSURERS (Mr. Peters and Mr. Lifson)

I am most interested in Mr. Peters' description of the "Caring program, under which several Blue Cross plans have worked with business, civic and religious organizations to subsidize insurance coverage for children who have neither public nor private insurance. As I understand it, these plans cover primary preventive and emergency health service at no cost to the family.

While I understand that the potential for such plans is necessarily limited, I wonder whether any consideration has been given to offering a commercial product which would cover children only, for a limited set of services. Even parents in uninsured families might be willing to purchase such coverage were the costs reasonable. For example, it has been suggested that such a product be marketed through the school systems.

Answer:

No, it is not possible under present law to offer such policies because of the excessive number and variety of state mandatory benefit laws. There are almost seven hundred such laws. The HIAA strongly recommends that the present ERISA pre-emption of these laws enjoyed by large, self-insured employers since 1974 be extended to insured plans so that insurers can design and market less expensive health benefit plans to small businesses, thus encouraging broader coverage of employers, spouses and dependent children.

QUESTION FOR PANEL OF INSURERS (Mr. Peters, Mr. Lifson)

Mr. Lifson's statement indicates that an increasing number of plans have increased or eliminated lifetime maximum benefit limitations. I assume that relatively few of the children covered by your plans exceed these maximums. How expensive is it for the employer and/or employee purchasing the plan to eliminate these maximums altogether, especially for dependents?

Answer:

The present cost of eliminating lifetime maximum benefit limits would not be great. Some companies feel, however, that a finite number, however large, is more concrete and gives a greater sense of security to the insured rather than no stated limitation at all. From a policy point of view, there is a concern over the wisdom of health insurance policies with no limits. Future technological developments are unknown and taking away or restricting benefits once contracted for is difficult at best, if not impossible. Most individual health insurance policies, for instance, are guaranteed renewable. Thus, in today's world of sky-rocketing health costs and rapid change, promising "unlimited benefits" for an unspecified number of years into the future seems unwise.

QUESTION FOR PANEL V (Mr. Peters, mr. Lifson)

How does case management work, for example, in the case of a parent who has a child with a chronic condition but does not know where to begin to seek the right services for that child?

Answer:

When case management becomes involved with the family of a chronically ill child, the first step is to assess the child's history, the specialists services that have been involved with the child if any, and the needs of the child and the child's family.

The case manager provides information on available government, voluntary, and private programs. Based on physician advice and the assessment of the child, resources are provided to the parents. The case manager assists the family with applications to appropriate programs and coordinates their services so there is no duplication. The family must be an active participant in this process in order to educate themselves and to prepare themselves for the future needs of the child. The case manager monitors the programs until the family is prepared to function independently of the case manager.

Is case management designed to improve access to special care that these children may require, or is it really more of a cost control system designed to channel these children to low cost providers?

Answer:

Case Management's primary goal is to achieve the best outcome, the optimal level of recovery and independence for each patient. This can only be done by providing specialized care to the individual child. We know that timely, appropriate, specialized care prevents complications, over-utilization of the health care system, and fragmentation of care. For this reason the best and most appropriate care results in cost savings. Low cost providers that do not provide appropriate care for these children result in increased expenditures over a period of time. Case managers direct the child to quality care and thereby provide cost savings over the lifetime of the child.

How much freedom of choice do these parents have to select providers?

Answer:

Case managers select two to three quality providers and ask the parents to evaluate them and choose one. This provides direction for the parents, yet still gives them freedom choice. If the parent chooses a provider the case manager is not familiar with, the case manager evaluates the appropriateness of that provider for the individual family. If the case manager believes the provider is not appropriate, the case manager explains why to the family, and encourages them to choose another provider.

Follow-up

If an individual with a chronically ill child has no health insurance, are there public or private networks for channeling these children to appropriate providers (similar to your case management programs)? Specifically, do you think that case management for these children would be an appropriate requirement under the Medicaid program?

Most Medicaid programs do have case managers to channel these children to appropriate providers. The Crippled

Children's Society (or similarly-named organization) of each state is the agency responsible for chronically ill children.

The difficulties we have seen with the Medicaid programs are inadequate staffing (too many cases per case manager) and inadequate numbers of programs for children. Many providers will not accept children eligible for Medicaid.(The reimbursement level is too low.). The programs that are available to such children are usually full and a long waiting list exists for each program.

The children who have the most difficulty are those whose family has a "borderline" income or equity in their homes. They cannot afford appropriate care, yet in order to qualify for Medicaid they must decrease their income or sell what little assets they have.

Case management is essential for all chronically ill children. However, low cost, overworked case managers are not the answer. Monies must be spent initially in order to achieve quality care and long term savings.

Senator ROCKEFELLER. Mr. Peters, in your statement, you indicate that employer group plans are less likely to cover dependents than employees and that a principal reason for this may be the cost of such coverage. This raises a couple of questions in my mind. One: Has the extent of coverage of dependents changed over time? How and why? Let's start with that.

Mr. PETERS. I believe that the extent of dependent coverage has changed over time, and that is in the good direction. We will be able to provide you with specifics in our own experience and trends, but there is a positive trend reflected in some of the work done by the previous speaker in the previous panel that suggests dependent coverage has been expanded by employers.

It still represents a significant gap, however, and the reason most often cited from our survey work is the cost. It is made available by the plans and by commercial insurers, but it is simply not at a price that the employer as the sponsor feels he can afford, along with wages and other benefits. So, it is a trade-off. He will likely pay for—and all generalizations are subject to exception, of course—but he will generally pay for the employee but he will not move to pay for the dependent.

Senator ROCKEFELLER. All right. We heard from earlier witnesses that health care costs among children are in fact unevenly distributed, with the vast majority of children who are relatively healthy incurring relatively lower costs. It seems to me that this is even more likely to be true in the working population. Why then is dependent coverage so expensive when the instance of expensive illness is so rare? Do you want to answer that, Mr. Lifson?

Mr. LIFSON. Dependent coverage includes both adults and children, so it also includes spouses. So, you have those expenses, plus, independent coverage, you have multiple children, averaging 2.3 children per family unit.

So while the relative expense per child may be low, you have multiple children; and that increases the total expense.

The other point is that employers tend to pay less on behalf of the employee for their dependents; therefore, the out-of-pocket expense to the employee is higher. And some employees make the choice of not covering their dependents.

Senator ROCKEFELLER. Mr. Peters?

Mr. PETERS. I would concur with that.

Senator ROCKEFELLER. All right. Also for both of you—if either of you wish to answer this—one of the most compelling arguments for improving public program coverage of maternal and parental care is the clear evidence that in the long run the costs to society of caring for disabled children far exceed the costs of investing in the care that could prevent those disabilities in the first place.

Do you, as insurers, and the employer that you work with, make similar assessments in deciding which services to cover, either for prenatal care or in assessing alternatives for treating high-cost chronic illnesses in children?

Mr. PETERS. We are right now engaged in a very, I think, thoughtful and deliberative process with the American Academy of Pediatrics in proposing what we are labeling as a model benefit for pediatrics and adolescents

Within the context of that will be a greater emphasis on this aspect of prevention. That is being reviewed at the end of this month by a medical advisory panel, and I think over the next several months will be articulated through all of our plans.

The history, I think, on why there has been resistance and a lack of attention to the preventive side of this equation is that, first of all, it has only been in recent years, I believe that people have come to appreciate the trade-offs, the cost-to-benefit if you will. We have not had definitive knowledge from studies of the cost benefit of investing in this preventive outcome.

Second, there has been a very strong bias among many individuals and organizations in our society to cover acute care—the high cost of acute care—episodic care, just as a general attitude.

And third, within the framework of insurance as a concept, insurance pools risk—it is a risk-pooling technique—and it is intended to avoid some catastrophic event. When you say pay for or cover preventive services, in a very real sense that is not insurance because it is a known fact; you are going to pay for a whole series of services and it is an absolute payment.

We are not denying that that is appropriate to do. We need to educate our employer groups and many other organizations of the kind of revelations that have been presented over the last several years, as studies come out, and say to us all: an investment in this preventive technique or strategy has real savings in a societal sense down the road five to ten years.

I think we are aggressively pursuing these techniques and policies and activities, as evidenced by the carrying of the program, "Beautiful Babies Right From the Start."

Senator ROCKEFELLER. Thank you. Mr. Lifson?

Mr. LIFSON. I think I concur with most of what has been said. I think the insurance companies have been promoting wellness and prevention for any number of years. Some of the specific interventions that one would take have traditionally been considered public health measures.

I look at my own experience. I received all my immunizations through the school system in New York City. I think we have moved away from some of that, and maybe we should reexamine whether or not we should go back to public health measures that many of the States and the Federal Government supported for many, many years.

Insurance companies have offered to employers to cover preventive activities. Some employers have put it in their plans. There was a survey done which, in 1986, showed that 30 percent of plans covered preventive and well baby care. I think we would like to see more plans do that.

I think people have found ways to manage the system. Insurance companies—Blue Cross and others—have been paying for those well baby services. They haven't been called well baby services, but they have been paying for them.

On the technology side, I think we look to the public sector in evaluating technologies, that is, the Food and Drug Administration and others. We have supported the Institute of Medicine's activities in this regard, and we will continue to do so.

Senator ROCKEFELLER. Gentlemen, thank you. It is just a bit after 1 p.m.; and in this odd process called the making of a hearing which you are both familiar with, we have to conclude this now. You both know well that not only what you say here but the questions that we will give you in writing and to which you will respond are a very important part of the public record.

I am not sure that all witnesses when they come, in some cases, from very far away and they wait all morning, and then they get to testify and there is one Senator and only a couple of questions, think their work has been worthwhile. That in fact is not at all the case.

The building of the public record is exceptionally important; and when we are getting into a subject like we are this morning in terms of children in the long term, it is exceedingly important. So, not only what you have said but what you will reply to us, hopefully, in writing is important. You both know that, but I want that to be clearly understood.

We are grateful for your presence. We are grateful for those who have preceded you.

This hearing is now adjourned.

[Whereupon, at 1:05 p.m., the hearing was adjourned.]

APPENDIX

ALPHABETICAL LIST AND MATERIAL SUBMITTED

Opening Statement of Senator Lloyd Bentsen
Finance Committee Hearing on
Children's Health Care Issues
March 23, 1988

Last fall, in introducing legislation to create a National Commission on Children, I indicated that I hoped to make 1988 the year during which child health issues would become the priority agenda item for the Committee on Finance.

This morning, we are holding the first in a series of hearings on health care issues affecting children. Few issues have prompted as much interest among members of this Committee. Already this year, I note that bills relating to infant mortality have been introduced by Senators Bradley and Durenberger, and that many other members of this Committee have joined as cosponsors.

The health care problems facing our children are complex and multifaceted, and we can no longer afford as a nation to ignore them:

> The United States ranks seventeenth among the developed countries of the world in infant mortality rate. We have made no progress in this area at all since 1985. A white infant born in this country is two-thirds more likely to die in his first year than a baby born in Japan. A black baby born here in Washington, or in many other of our nation's cities, is more likely to die before its first birthday than a baby born in Jamaica.

The Guttmacher (GOOT-mock-er) Institute recently reported that as many as 35% of American pregnant women get less than sufficient prenatal care. This, despite evidence that investments in prenatal care are returned three to one during the first year of an infant's life.

Health care costs can become an issue even for families with incomes well above the poverty line. One in five American children has no public or private health insurance. Of 37 million uninsured Americans, 12 million are children, 9 million of whom are the dependents of workers who lack insurance against any health care costs.

Finally, every American family faces the specter of a high-cost, catastrophic illness -- often of a chronic nature. The parents of a catastrophically ill child suffer not only untold emotional stress, but can see their life savings wiped out by costs not met by even the most comprehensive private insurance plan. While the number of such children is small, the costs for an individual family can be devastating: an estimated 19,000 children incur health care costs in excess of $50,000 a year.

Today, we will hear from witnesses from government and the private sector about the way in which the current patchwork health care system meets the needs of America's children. The system has many components: Medicaid for low-income children, the Maternal and Child Health block grant program, employer-sponsored health insurance that covers the majority of the nation's children and Medicare for a small number of children with end-stage kidney disease.

There are success stories to be told, I'm sure. On the other hand, we have much farther to go before we can be certain that we have done what we can to assure that all children have access to adequate and affordable health care. Failure to grapple with the problems faced by children and their families will shortchange this country of the strong and healthy leaders we need in the next generation.

It is not an exaggeration to say that America's children are our future. We can choose to invest in them. Or we can close our eyes to the growing problem of inadequate health care coverage for children. There is no one who is more aware than I of the difficulty of improving child health programs in a time of budget constraints. But we should not be deterred from a task that both compassion and cost-effectiveness tell us we must meet.

I am confident that my colleagues join me in welcoming our witnesses this morning. In particular, I want to extend a warm welcome to Governor Mabus from Mississippi who, first as State auditor and now as Governor, has played a major role in implementing a much-improved Medicaid program in his State.

Statement of

Sarah S. Brown
Study Director
Institute of Medicine
National Academy of Sciences

Before the Committee on Finance

United States Senate

March 23, 1988
Washington, D.C.

STATEMENT

Good morning. I was very pleased to be asked to talk to the Senate Finance Committee today. I will speak mainly about prenatal care this morning and trust that others will cover additional topics in maternal and child health.

The points I wish to make derive from two activities conducted by the Institute of Medicine, a component of the National Academy of Sciences: a report published in 1985 on preventing low birthweight, and a project now nearing completion on how best to draw women into prenatal care early in pregnancy. I have served as the study director of both projects, which have been funded by a consortium of private foundations, voluntary groups, and the U.S. Public Health Service. My remarks also draw on recent experience serving as the co-chairman of the District of Columbia's Board on Maternal and Infant Health, a group appointed by the Mayor to advise him on ways to reduce the District's high infant mortality rate.

Many discussions of maternal and child health, including today's hearings, are shaped by a growing sense that the current rate of infant mortality in the U.S. is too high - 10.6 deaths per 1,000 live births - a rate which is higher than at least 16 other countries, including most Western European nations. It is also now recognized that the majority of infants who die in the first year of life are born weighing 2,500 g (about 5 1/2 lbs.) or less, which is termed "low birthweight." Although the infant mortality rate has decreased annually for years, the pace at which it is declining has slowed recently, a disturbing phenomenon whose causes have most recently been assessed by the U.S. Congress' Office of Technology Assessment.

In considering how to break the current stagnation and decrease the rate further, a key historical fact must be understood. Put in overly simplistic terms, the majority of progress in the U.S. since 1960 in reducing infant mortality has been due to stunning advances in neonatology, particularly as seen in newborn intensive care nurseries (ICNs), where increasing proportions of at-risk, low birthweight infants are helped to survive. This great success story is easily documented: in 1960, 73% of all very low birthweight infants (a highly vulnerable group, weighing only 1500g or less) born in hospitals with high-quality ICNs died in their first 28 days of life; by the early 1980s, this percentage had declined to 27%. The net result of such strides is that a tiny, sick newborn cared for in a high quality facility in the U.S. has a better chance of growing successfully into healthy childhood than a similarly at-risk infant anywhere else in the world.

But there is deep concern about whether the salvage efforts of ICNs should remain our principal means of reducing infant mortality. The hesitation is based on at least four issues: first, intensive care for newborns can be very expensive, with some individual cases costing $150,000 or more; second, there is concern about the role of such services in producing an increased number of individuals with handicapping conditions; third, the science of neonatology may not be able to continue generating the endless stream of life-saving technologies (such as artificially assisted ventilation) needed to make additional, major reductions in neonatal mortality; and, finally, as ever smaller infants are saved, the ethical issues surrounding abortion, fetal viability and definitions of human life intensify.

The Institute of Medicine committee that developed the 1985 report concluded that although continuing to improve the medical care of newborns is an important approach to reducing infant mortality, it should be matched by an equal commitment to producing healthier, heavier babies in the first place. That is, we should concentrate more of our efforts on preventing major precursors of infant mortality--mainly low birthweight--and not rely exclusively on after-the-fact interventions to improve infant survival.

With this focus on prevention its guiding principal, our 1985 report recommended five broad classes of activities to reduce low birthweight (and therefore infant mortality):

1. Reduce the risks associated with low birthweight before pregnancy by means of risk identification and counseling, health education and family planning.

2. Increase participation in early and regular high-quality prenatal care.

3. Expand and improve the content of prenatal services.

4. Mount an extensive and sustained public information campaign on a few key concepts of reproductive health.

5. Conduct a multifaceted research program on the causes of low birthweight and on ways to prevent it.

Although the balance of my remarks concern only one aspect of this comprehensive approach--prenatal care--I want to underscore the significance of those I am not discussing further. Preconceptional health education and family planning, for example, have great potential for improving pregnancy outcome; I hope that these approaches and others will be covered by subsequent witnesses.

The significance of prenatal care rests, in part, on the broad and deep consensus that it is an effective intervention, strongly and clearly associated with improved pregnancy outcomes. Declines in rates of low birthweight, maternal mortality and infant mortality have been repeatedly linked to full participation in high quality prenatal care that offers a wide variety of services and social supports, and is well connected to hospital-based services such as intrapartal and neonatal care. Moreover, the evidence suggests that prenatal care is especially important for those women at highest risk because of their social condition, their health status, or both.

The importance of prenatal care is also underscored by evidence of its cost-effectiveness, particularly for low income women who often obtain inadequate care during pregnancy and who are at increased obstetrical risk. For example, in 1985, the Institute of Medicine calculated that each additional dollar spent on providing more adequate prenatal care to a cohort of low income, poorly educated women could reduce total expenditures by $3.38 for direct medical care of their low birthweight infants during the first year of life. Other investigators have computed different cost-saving ratios, but virtually all analyses find evidence of cost-effectiveness.

Despite the proven value of prenatal care, not all women obtain such assistance while pregnant. In fact, in 1985, approximately one fourth of all babies born in the U.S. were to women who failed to begin prenatal care early in pregnancy and over 5% were to mothers who received little or no care at all. For certain subgroups, the rates are far worse. For example, of babies born to black teenagers, only 47% were to mothers who began care in the first trimester, and 14% were to mothers who had little or no care at all. Moreover, recent trends in the use of prenatal care are not improving for all groups. In 1985, for the sixth consecutive year, no progress was made in reducing the percentage of infants born to women who received late or no care. For blacks, the size of this group actually appears to be increasing. National Center for Health Statistics natality data show that in 1980, 8.8% of black infants were born to mothers having had seriously inadequate prenatal care; by 1985, this number had grown to 10.3%.

Why are these utilization rates so poor? Why is it, for example, that in some areas of New York City, over half of all babies are born to women who received no prenatal supervision at all, or just a few visits close to the time of delivery? Our current committee has spent close to 18 months puzzling over this issue, among others, trying to understand barriers to prenatal care. In our view, the obstacles cluster in two groups. The first consists of external factors—the way prenatal services are financed, organized and actually offered. Common barriers in this group include absence of either public or private insurance to help pay for care, limited capacity in the prenatal clinics relied on by low income women, too few private providers willing to care for Medicaid-enrolled pregnant women, transportation problems, services offered at inconvenient times and places, negative attitudes of providers, and such inhospitable clinic practices as long waits to see a physician and poor provider continuity.

The second group of barriers to care is internal and includes denial of pregnancy; fear of doctors, medical procedures, and hospitals; apathy or ambivalence about whether to continue a pregnancy; a belief that prenatal care is not useful or important, or, more accurately, that other things are more important; fear of others learning that one is pregnant; and related factors.

The key question for policy makers is: which barriers loom largest overall, accounting for most of the poor use of prenatal care? Our current study group has consulted a wide variety of data sources to answer this question. We have reviewed published and unpublished articles; studied over 30 programs around the country designed to draw women into care early in pregnancy and, in particular, reviewed results of over 20 surveys in which women themselves have been asked about problems they encountered in trying to secure prenatal serv[illegible]ndings and conclusions will be in our forthcoming report. [illegible] let me say now that system-based, external barriers are strikingly prominent in all the data we have reviewed. Numerous programs and research studies suggest that when system barriers are lessened—when financing in particular is adequate, when providers are plentiful and the system is easy to enter—prenatal care use improves significantly. Ample vignettes from around the country illustrate this point:

- In Onondaga County, New York, by simply opening several new clinic sites in areas where prenatal care use was low, rates of first trimester registration increased significantly in the target area, particularly for teenagers.

- By simplifying the process of applying for Medicaid coverage, and by linking pregnancy testing to prenatal care, the wait for a first prenatal visit at a major New York hospital dropped from 90 days to two weeks.

- In Lea County, New Mexico, low-income women recently had virtually no place to go for prenatal care. The private doctors took few indigent patients and no clinic services were available. When the support of the private physicians was enlisted and a clinic opened in the local health department, the county hospital documented a sharp drop in the number of women arriving at the hospital in labor having had little or no prenatal care.

Unfortunately, though, the system too often doesn't function well, particularly for poor women. Our 1985 report concluded, very pointedly, that our discouraging rates of participation in prenatal care primarily reflect the nation's patchwork, nonsystematic approach to making such services available. Many programs have been developed in past years to extend prenatal care to more women, and in some areas a modest degree of success has been achieved. But along the way we have also created a very complicated tangle of programs and policies with probable losses (never measured, incidentally) in efficiency, managability and effectiveness.

This overarching conclusion led the 1985 Institute of Medicine group, and will probably lead our current committee, to call for a fundamental restructuring of the way in which maternity care is defined, organized and financed in the U.S. Although we have not recommended a specific plan, we believe that if the political will were strong, a new approach to maternity care could be developed and put in place.

As you might imagine, such clarion calls are also accompanied in our reports by more concrete suggestions. I will highlight three. The first concerns Medicaid. Given the potency of financial barriers to prenatal care (most recently documented in the U.S. General Accounting Office report, Prenatal Care: Medicaid Recipients and Uninsured Women Obtain Insufficient Care), common sense alone suggests that programs which can reduce such obstacles will result in better use of this key preventive service; and in fact, such is the case with Medicaid. By providing very poor women with a source of payment for prenatal services, the program successfully lessens the controlling influence of economic status in getting basic health care. Accordingly, expanding Medicaid to cover increasing numbers of low-income pregnant women--through recent legislation and through such bills as S. 2046 and S. 2122, now under consideration--represents important progress in removing a major obstacle to care.

Expanding eligibility, however, is only one of several needed changes in Medicaid. As you probably know, women who finance their prenatal care through Medicaid still see a doctor less often in pregnancy than women with private insurance; in some studies, they even receive less care than women with no insurance at all. At least two reasons account for this. First is the nature of the enrolled population itself. It is typically very poor, inner city resident, inadequately educated, often minority - sociodemographic attributes that are closely associated with poor use of prenatal care. But perhaps more important in explaining the limited use of prenatal care by women enrolled in Medicaid is the enormous complexity of the program. With regard to the application process, for example, reports from the front lines reveal an administrative tangle of immense proportions--an enormously complex, ever changing system that is difficult for many case workers (let alone applicants) to understand. The application process can be demeaning and so time consuming as to almost ensure that pregnant women relying on the program won't begin needed care until many weeks into pregnancy. A recent publication of the Alan Guttmacher Institute, Blessed Events and the Bottom Line, has detailed these application problems and many others carefully. That report points out, for example, that most Medicaid programs make little effort to alert low-income women to their potential eligibility. Other groups have described many other administrative problems in the program, particularly those that seem to discourage provider participation. These shortcomings, and others, are no doubt well know to this Committee.

Such evidence suggests that eligibility expansion must be accompanied by major administrative reforms. With regard to the application process, for example, reforms are needed to shorten, simplify and dignify it; to move it as far away as possible from the welfare milieu; and to change a case worker's orientation from "How can I find a way to keep this applicant off Medicaid," to "How can I welcome her onto the program today?"

A second point concerns private insurance. Whatever criticisms can be leveled against the 54 Medicaid programs can also be made about the nation's thousands of private health insurance plans. Recent studies reveal that the presence of private insurance does not ensure that comprehensive prenatal services can be secured, nor does it necessarily protect women from significant financial burdens. Gaps in coverage, imposition of "waiting periods" that may exclude those already pregnant, the limited insurance options for unemployed or part-time workers, shifts and increases in premiums, and deductible and co-payment requirements, have placed new and complex burdens on women and young families. The net result of such problems is that some 5 million women 15-44 years of age have private policies that do not cover maternity care.

A particular limitation of private insurance is its link to employment. In the United States, over 80% of all privately insured Americans under age 65 are insured through their employer. Employers who hire low-paid or part-time non-manufacturing and seasonal workers, and small employers, are less likely to furnish health insurance. Since women historically have been disproportionately represented among low paid, part-time, and seasonal workers, they traditionally have been significantly less likely to be privately insured.

Even employees and families who are privately covered are frequently covered less extensively than in the past. The Pregnancy Discrimination Act of 1978, which mandates that private insurance plans provide coverage of routine maternity care, does not apply to employers of fewer than 15 employees, and not all states have enacted remedial legislation of their own to close this gap. Furthermore, such state laws, where applicable, do not apply to employers that "self-fund" their insurance coverage and thus are exempt from state regulations under the Employee Retirement Income Security Act. As a result, insured employees working in small firms may have no coverage for maternity care at all.

A third focus of our group is on the content of prenatal care. As you may know, considerable confusion exists about what prenatal care should include, and there is concern about the substantial variation in what pregnant women receive, even though written standards do exist. Some professionals supplement basic medical care with a rich array of education and nutrition services, such psychosocial supports as home visiting to high-risk pregnant women and new mothers, help with smoking cessation and with managing other addictive behaviors, and related forms of counselling and assistance . Other providers limit prenatal care to medical supervision only. There is also concern that the quality of care is inadequate in some settings, and in particular, that it is not always carefully tailored to an individual woman's risks and needs. It has even been suggested that substandard care might account for part of our seemingly high infant mortality and low birthweight rates, and might also help to explain why some pregnant women begin prenatal care but then stop, or fail to register until late in pregnancy or at all.

In response to such factors, at least two groups are currently at work to define even more carefully the assessments and interventions needed during pregnancy—the U.S. Public Health Service's Expert Panel on the Content of Prenatal Care, and DHHS' Preventive Services Task Force. The reports of these groups are likely to strengthen the consensus that high quality prenatal care should consist of many, varied components—medical services, education, psychosocial supports and the other care elements noted earlier. As these content specifications evolve, major purchasers of prenatal services, such as Title V and Medicaid, need to make sure that their state and local agencies finance comprehensive, multifaceted care during pregnancy and that public dollars are not used to support either poor quality care or care that is focused on medical issues only.

I will conclude by again raising the issue of international comparisons. As elaborated recently by Dr. C. Arden Miller, chairman of the Department of Maternal and Child Health at the University of North Carolina, many other countries approach the provision of care to pregnant women as a form of social investment. They have developed relatively simple, well-functioning maternity systems, often with more meager resources to draw on those available here. Prenatal care, like health services generally, is made readily available with minimal barriers or preconditions in place; and it is closely connected to numerous social and financial supports for pregnant women and young families. Such services are seen as part of a broad social strategy to protect and support childbearing and to produce healthy future generations. As a result of this comprehensive approach, many European countries report that virtually all of their pregnant women begin prenatal care early in pregnancy. Not surprisingly, their rates of maternal mortality, low birthweight and infant mortality are often lower than those in the U.S.

The profoundly different concept of maternity care that some other countries hold was recently explored at an international hearing sponsored by the National Commission to Prevent Infant Mortality. By profiling the way that other countries organize care for pregnant women, the hearing record reveals how fragmented, overly complex and excessively technological our own approach is. The statements also contain many ideas that deserve careful consideration in this country and by this Committee. Such international perspectives can help us all to look beyond our current morass of programs to devise an improved system of care and support for pregnant women, infants and the families in which they live.

STATEMENT BY

SENATOR JOHN H. CHAFEE

AT

FINANCE COMMITTEE HEARING

ON

THE STATUS OF CHILDREN'S HEALTH CARE

MARCH 23, 1988

Mr. Chairman, I commend you for holding hearings on the critical issue of children's health care.

As a member of the Senate Finance Committee and the Subcommittee on Health one of my highest priorities has been to provide widespread and effective health care services for children -- especially those who live in families with limited income.

Since 1984, we have been slowly moving forward on this issue. In the Deficit Reduction Act of 1984 we were able to include a small expansion of the Medicaid program to provide voluntary coverage to children up to the age of five in families with incomes below state eligibility standards and mandatory coverage of low income women who were pregnant for the first time but were not eligible for Medicaid because they would not be eligible for AFDC benefits until the child was born. In the Consolidated Omnibus Budget Reconciliation Act 1985, we were able to extend prenatal care coverage to all pregnant women who were beneath the state income standards. In the Omnibus Reconciliation Act of 1986, we included a provision to allow states to cover children up to age five (on a staggered basis) and pregnant women up to the federal poverty level even if those individuals were not eligible for the State AFDC program.

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Just last year, we were successful in including a provision in the reconciliation conference agreement which would allow states to extend Medicaid coverage to pregnant women and children up to age one who are below 185% of the federal poverty level and to all poor children up to age 8.

Although these initiatives have started us on our way to a system of more effective health care for children and low-income individuals, they are not enough. If we are to truly address the needs of children, and other individuals without access to health care services, we must begin with a broad view of the problem and we must be constantly alert in seeking solutions.

Infant mortality and low birth weight among babies are two of the most distressing problems facing our Nation. Eleven babies die out of every 1,000 infants born in this country. Few events can be as tragic as the death of a baby. Many such deaths can be prevented with proper prenatal care. The future of our Nation depends on our children, and they deserve a better chance to survive and to be healthy.

The United States has one of the world's best programs for the treatment of low-birth-weight babies. Yet, we have a poor prevention program and our rate of low-birth-weight babies is higher than 11 other countries. According to the National Academy of Sciences, the rate of low weight births CAN BE REDUCED BY MORE than a tenth through improved prenatal care. The Academy estimates a cost-benefit ratio of $3.38 saved in the first year of a child's life for $1 spent in prenatal care.

When the United States has higher infant mortality rates than 11 other developed countries, we must ask why. When low birth weight is excessive among the poor, the poorly educated and those who do not receive proper prenatal care, we must take action.

Even during a time of fiscal restraint it is sound economic policy to invest in the health of our mothers and children who are poor. Investment in improved pregnancy outcomes has enormous future returns in both human and fiscal terms.

But, the needs of children and low-income families go beyond prevention services. In the debate on catastrophic health care in Congress, those under 65 have been ignored. I believe that if we are truly interested in addressing catastrophic health care expenses we must look at both the old and the young.

More than one third of those without any health care insurance live in families with incomes below the poverty level, another one third live in families with incomes between 100 and 200 percent of the poverty level.

There are other individuals who, even if they could afford to purchase insurance, are without access to private health care insurance. These are people who have been denied private health insurance -- for example an individual with what is known as a pre-existing condition.

Finally, there are individuals with chronic illnesses who exhaust their private health care insurance and have nowhere to go but into poverty to qualify for medicaid benefits. For families with a chronically ill child this is a real threat.

Many of us on this Committee have introduced proposals to address these problems and I hope that the witnesses today will share their views on these ideas.

Many of us joined Senator Bradley in introducing S. 2122, which expands on previous efforts to provide health care to pregnant women, infants and poor children. First it would require that states provide Medicaid coverage to all children and pregnant women below 100 percent of the federal poverty level. Second, it would provide incentives to physicians and other health care providers in order to encourange them to accept Medicaid patients.

Third, it would allow Medicaid to purchase WIC services for poor children and pregnant women.

I have introduced more sweeping legislation -- S.1139, MedAmerica. This bill would build on the existing Medicaid program in three ways:

First, it would sever the tie between Medicaid and cash benefit programs -- such as AFDC and SSI. As a result, states would have the option of providing Medicaid benefits to anyone whose income is below the federal poverty level, regardless of whether or not they qualify for cash welfare programs.

Second, states would have the option to allow individuals -- the so-called "working poor" -- whose incomes are at or near the federal poverty level to purchase health insurance through Medicaid for an income-adjusted premium, not to exceed 5% of the individual or family's adjusted gross income.

Finally, states would have the option to allow persons with family incomes and resources in excess of 200% of the federal poverty level to purchase Medicaid benefits if they have been excluded from private health insurance coverage because of a medical impairment or disability or if they have exhausted one or more benefits under their private insurance plans.

I have also introduced a proposal to expand on the current Maternal and Child Health Block grant program -- S. 1537. This legislation would increase the authorization for the MCH program in order to provide assistance to families who face the devastating problems associated with children who have serious illness.

I look forward to listening to the testimony today and I hope the witnesses will help us find a way to move forward on these troubling problems.

Hearing on Children's Health Care Issues

Statement by John C. Danforth

Mr. Chairman, thank you for holding these hearings on children's health care issues and thus focusing the attention of this Committee on our nation's most valuable resource. It is far too common for the Congress to forget children in its development of public policy. Frequently, this body focuses on solutions to immediate problems presented by vocal lobbyists rather than on plans and ideas for the future of our country. Clearly, the problems facing our children deserve careful analysis and thoughtful policy development. I look forward to working with you and the other members of our Committee in an effort to ensure a better future for our children.

A consensus on the importance of focusing resources on children seems to be developing in our country and in the Congress. This agreement has evolved for a variety of reasons, but one of the most compelling is the increasing poverty among those under the age of 18. Children are now the poorest segment of our society. In my own state of Missouri, an estimated 247,000 children live in families with income levels below the poverty line. They represent 18.6 percent or one in five of all children in the state.

Poverty is often accompanied by a lack of access to proper health care coverage and other impediments to proper growth and development. Clearly, our nation must focus on the needs of these children and develop creative solutions to their problems if we are to have a promising future. Specifically, in the health care arena, we must assure that children in our country are born healthy and are physically able to reach their full potential. This means that pregnant mothers need to be given proper prenatal care, and children need to be immunized against diseases and provided the range of suggested well-child care services. Preventive care is not only humane, but a very effective investment in our future.

In the Omnibus Budget Reconciliation Act of 1986, we began a renewed effort in preventive care by focusing on the fight against infant mortality. Experts were telling us that progress had slowed in this area and that the United States was tied for the highest infant mortality rate among the industrialized countries. We were told that about 40,000 or one percent of all babies, die before their first birthday. In Missouri, the infant mortality rate in 1984 was 10.4 deaths per 1000 live births. One in five babies were born to mothers who did not receive early prenatal care. It is appalling that the infant mortality rate of a nation as technologically advanced and wealthy as ours ranks so far behind most other industrialized nations. In an effort to increase the fight against infant mortality and low birth weight, we took an historical and important step with the Medicaid program. Throughout its history, the Medicaid program had been linked to the receipt of welfare benefits and thus somewhat arbitrary in the people that it has covered. Two years ago, we removed that link for pregnant women and some children. This new provision extended the option to states to provide Medicaid to these segments of the population up to the federal poverty level. I am pleased to say that on January 1, 1988, Missouri adopted this option. The State projects that 4,682 additional pregnant women will receive Medicaid benefits annually. In addition, 624 women and 2,394 children will receive case management services.

Most recently, I cosponsored the Medicaid Infant Mortality Amendments of 1988. This bill will continue the fight against infant mortality by mandating that all states provide health care coverage for pregnant women and very young children up to 100 percent of the Federal poverty level and increase provider participation in the Medicaid program. Unless we, as a nation, commit to the fight against infant mortality, the United States will have little chance of meeting the Surgeon General's goal of reducing the infant mortality rate to nine deaths per 1000 live births by 1990.

In addition to the Medicaid efforts, I have been actively involved in securing additional funding for the Supplemental Food Program for Women, Infants and Children (WIC). This is an important program that can work in conjunction with Medicaid to ensure that pregnant mothers receive basic nutrition and prenatal health care. Numerous evaluations have demonstrated the extraordinary benefits and cost-effectiveness of this program. A recent five-year national evaluation of WIC issued by the Department of Agriculture found that WIC reduces infant mortality, reduces the incidence of premature births (which is a leading cause of infant mortality), increases the number of low income women women receiving adequate prenatal care, improves diets and nutritional intake, and even appears to improve cognitive development among children. In addition, a study conducted by the Missouri Department of Public Health indicates that every dollar spent on the prenatal component of WIC averts $.49 in Medicaid expenditures during the first 45 days of life alone. Last year, we were able to secure $150 million over current services for the WIC program in the budget resolution. While the Appropriations Committee did not fund the full amount, an additional $87 million was provided in a year of tight budget constraints.

Clearly, there is much more that needs to be accomplished in the area of preventive care. A series of recent studies by the Office of Technology Assessment, the General Accounting Office and the Institute of Medicine are all providing insights into the health care needs of pregnant women and children. It is my hope that in these hearings we will be able to elaborate on those needs and develop cost effective solutions. Again, thank you Mr. Chairman for focusing the Committee's attention on children. Our country has no more important or valuable resource than our children.

STATEMENT

OF

SENATOR DAVE DURENBERGER

SENATE FINANCE COMMITTEE HEARING ON CHILD HEALTH

March 23, 1988

I'm very pleased that the Senate Finance Committee, led by my distinguished colleague Senator Bentsen, is turning its attention to the subject of child health. I would like to commend Senator Bentsen for his leadership in this area, and for calling this hearing today. I hope that we can use the occasion as a spring-board for needed action in this area.

The issues before us are profound in their effect on the future of our nation. Quite literally, our most precious national resource is at risk. Our future prosperity depends on our ability to enhance the prospects and productivity of the next generation. In order to do this, we must begin by protecting our children's health.

For a relatively well-off country, we have shocking statistics about children. First, children make up 40% of the poor in the United States. The earning capacity of their parents under age 30 has dropped by 30% in the last 10 years. Mr. Chairman, of the four- and five-year-olds in today's America, one in six have no health insurance. Add to this the facts that about 10 percent of all babies in this country are born with major health problems, and 40,000 infants die annually during the first year of life, and we have the makings of a national crisis.

I don't mean to imply that we have done nothing to improve this disastrous situation. Last year, Senator Bradley and I introduced a bill that would allow States to enroll pregnant women and children in Medicaid up to 185 percent of the Federal poverty level. As you know, that legislation was passed by Congress, and will greatly increase the opportunities for decreasing infant mortality and improving health for many pregnant women and children.

However, a more comprehensive next phase is necessary in this continuing evolution of legislation to decrease infant mortality and expand coverage to poor, uninsured pregnant women and infants. I recently introduced legislation that will go the next step and require that all States, at a minimum, provide Medicaid coverage for prenatal care, delivery, postpartum care, and infant care during the first year of life to low income women and infants up to the Federal poverty level. I also ethusiastically cosponsored Senator Bradley's most recent Medicaid expansion bill.

We must enact one of these pieces of legislation. Studies conducted by the Institute of Medicine, the U.S. General Accounting Office, the Alan Guttmacher Institute, and many others have substantiated that prenatal care reduces both infant death rates and low birth weight infants. The infant mortality rate is 9.7 per 1,000 live births among infants whose mothers begin prenatal care during the first trimester of pregnancy, and 48.7 for those infants where the mother had no prenatal care. Women who receive insufficient prenatal care are about twice as likely to have a low birth weight infant. Thirty-four percent of all pregnant women get insufficient prenatal care; 47 percent of these women are poor. This is unacceptable. We must provide better alternatives for the pregnant women of this country, and a real chance for a healthy start in life for all newborns.

Infant mortality is not the only reason we need to ensure the health and future productivity of our children. Another serious gap in our health insurance system - coverage for low-income children with special health care needs must be filled.

Nationwide, an estimated 4 to 5 percent of all children under the age of 18 suffer from a chronic illness or disability that significantly limits normal childhood activities. Juvenile diabetes, and severe asthma are examples of such chronic illnesses. Whatever the specific disease, conditions classified as chronic share certain characteristics: They are costly to treat; require regular health care; may run an unpredictable course; and interfere with daily life and normal growth and development.

Good, regular health care, however, can enable a chronically ill child to function at his or her optimum, avert more costly hospitalization and emergency situations, prevent complications, and increase the child's chances of a full and productive life. Unfortunately, however, approximately one-third of poor children and one-fourth of near poor children with chronic illnesses are uninsured. Many others are underinsured. Without adequate health insurance, these children are unlikely to receive the health care they desperately need.

For this reason, last October I introduced the Medicaid Chronically Ill and Disabled Children Amendments of 1987, a bill to amend Title XIX of the Social Security Act to allow states the option of extending Medicaid coverage to children with chronic illnesses and disabilities in low-income families up to 185% of the poverty level.

We've got to make children our highest priority while we compensate for our past failures in public programs.

As Dr. Richard Reece said in a recent editorial in Minnesota Medicine (March, 1988):

" There are overwhelming problems engendered by widespread permissiveness, the disintegration of the family, and the overindulgence and consequences that ensue--drug and alcohol tobacco addiction, unwanted pregnancies and maternal deaths, sexual abuse and prostitution, psychological disorders and suicides, and violence and death."

We must stop allowing these terrible things to happen to our children!

STATEMENT OF SENATOR JOHN HEINZ
COMMITTEE ON FINANCE
MARCH 23, 1988

John Heinz

MR. CHAIRMAN, I AM PLEASED THAT THE COMMITTEE HAS AGAIN TURNED ITS ATTENTION TOWARD THE FUTURE, TO AMERICA'S CHILDREN. THIS NATION WAS FOUNDED ON A COMMON GOAL BEST STATED 100 YEARS AGO BY FREDERICK DOUGLASS, "A FAIR START AND AN EQUAL CHANCE IN THE RACE OF LIFE."

YET, THE UNITED STATES STILL REMAINS ONE OF THE MOST DANGEROUS PLACES IN THE INDUSTRIALIZED WORLD TO BE BORN. THERE IS A COMPELLING NEED FOR NATIONAL LEADERSHIP TO ADDRESS THE NATIONAL TRAGEDIES OF INFANT MORTALITY AND LOW BIRTH-WEIGHT.

RECENT STATISTICS RELEASED BY THE CHILDREN'S DEFENSE FUND SHOW THAT FOR THE FIRST TIME SINCE 1960 AMERICA'S INFANT MORTALITY RATE HAS SLIPPED. FOR A BLACK INFANT THE PICTURE IS MUCH WORSE. THE FACT IS THAT A BLACK INFANT BORN IN AMERICA IS LESS LIKELY TO LIVE TO THE AGE OF ONE THAN A BABY BORN IN CUBA, BULGARIA, OR COSTA RICA.

STUDIES HAVE SHOWN THAT GOOD PRENATAL CARE, STARTING EARLY IN PREGNANCY, CAN BRING AN END TO THIS ONGOING

TRAGEDY. FOR THIS REASON, THE COMMITTEE HAS AUTHORIZED OPTIONAL MEDICAID COVERAGE OF POOR PREGNANT WOMEN, INFANTS AND CHILDREN. AND, THERE IS GOOD NEWS TO REPORT. STATES HAVE MOVED MORE RAPIDLY THAN EXPECTED TO ADOPT MEDICAID COVERAGE FOR PREGNANT WOMEN AND CHILDREN LIVING BELOW THE POVERTY LINE.

I AM PLEASED TO REPORT THAT THE COMMONWEALTH OF PENNSYLVANIA WILL JOIN THIS FIGHT BEGINNING ON APRIL 1, 1988. ALSO, I EXPECT THAT THIRTY-TWO STATES WILL MAKE MEDICAID SERVICES AVAILABLE DURING PREGNANCY BY THE END OF THIS YEAR. IN THIS CASE, AN OUNCE OF PREVENTION MAY BE WORTH A TON OF CURE.

OUR NATIONAL INTERESTS, HOWEVER, MUST EXTEND BEYOND INFANTS TO THE BROADERS ISSUES OF HEALTH CARE FOR CHILDREN GENERALLY, AND IN PARTICULAR THOSE CHILDREN WHO FACE CHRONIC ILLNESS. TODAY'S PANEL OF EXPERTS WILL REVIEW THE HEALTH NEEDS OF ALL OUR CHILDREN. I AM PARTICULARLY INTERESTED IN THE INSTITUTE OF MEDICINE'S RESEARCH PROJECT ON HOW BEST TO ENCOURAGE **EARLY** PRENATAL CARE. SO I AM ANXIOUS TO REVIEW TODAY'S TESTIMONY.

THANK YOU, MR. CHAIRMAN

Statement
# of the
HEALTH INSURANCE ASSOCIATION OF AMERICA

on
CHILDRENS HEALTH CARE

Before the
Senate Finance Committee

March 23, 1988
Washington, D.C.

I am Arthur Lifson, vice president of Equicor, Inc. - a joint venture of the Equitable Life Assurance Society of U.S. and the Hospital Corporation of America. Today I also represent the Health Insurance Association of America. The HIAA is a trade association, representing some 335 insurance companies. Our members write over 85 percent of the private health insurance provided by insurance companies in this country. All of these companies design and underwrite private insurance plans that cover children as dependents of policyholders as well as directly under individual plans. Many of the member companies use case management services in administering their plans.

While the focus of this hearing is children, it should be recognized that most Americans are covered under public or private programs for the reimbursement of medical expenses. The health insurance industry, however, is deeply concerned about the some 35 million or 15% of the American public who are not so covered, and has begun to promote a series of proposals to close that gap in coverage.

The industry believes that the national surveys published concerning the extent of health insurance coverage fairly represents the order of magnitude of the problem we all face. As in the population as a whole, less than 15% of children lacked public or private health insurance coverage in 1986. Of the more than 85% that were covered, 70% of them were covered by private plans and 15% by public ones, principally Medicaid. Throughout the 1980's, Congress has taken several steps to expand the eligibility of poor children for the Medicaid program. As a result of those changes in law, it is reasonable to assume that the population of uninsured children might be somewhat smaller than current estimates show.

As is true with older Americans, approximately 85% of the children covered under private health benefit plans are covered through employee sponsored ones and 15% are covered under individually underwritten plans sponsored by insurance companies, Blue Cross plans, and HMO's. Typically, these are major medical plans which provide comprehensive acute care benefits after satisfying a modest deductible. The vast majority contain a limit on out-of-pocket expenses. Plans vary widely. The most common deductible, for example, is $100. 80% of plans have a limit on out-of-pocket expenses of $2000 or less.

In recent years, the degree to which preventive health care services are covered by private insurance health plans has increased substantially. A 1984 HIAA survey of member companies showed that approximately 20 percent of the employees' dependents covered by employer sponsored plans made provision for well baby and child care, and slightly over 50 percent had coverage for home health care. Just two years later, almost 30 percent of the plans had coverage for child health care and over 70 percent covered home health care services.

Private coverage typically includes the full range of inpatient and outpatient, diagnostic and treatment services. New technologies and procedures are covered regardless of cost once the Food and Drug

Administration, the Council on Medical Specialties or other professional review organizations have vouched for their efficacy. They are commonly excluded while in their experimental phases.

In recent years, the financial protections afforded under private policies have steadily increased with regard to catastrophic bills. Maximum benefit levels have typically been raised to $1 million or more. In 1984, nearly one-fourth of all employers had unlimited benefit levels. Data from 1986 on new or revised policies show that nearly 33 percent of all plans for companies with 25 to 499 employees had unlimited benefits levels. The same annual showed deductibles have increased from less than $100 to $250 per year. Given the substantial increase in medical care expenses in recent years, such an increase is not unreasonable and is designed to maintain the value of the deductible in constant dollar terms.

One of the recent developments that has made it possible for insurance companies to provide such expanded benefits while controlling the expenses of those benefits has been the development of case management services. Under a case management approach an insurer working with the insured, their family, and their medical practitioners designs and implements a plan for the care for the individual. The care plan often includes items of services not covered under the plan, but necessary to assure high quality and economical care. These services are paid when part of an approved case management plan.
For example, my company routinely provides for travel and hotel expense for a family member when we suggest a burn center far from the insureds hometown. This approach is used with relatively low frequency, high expense conditions.

For children the diagnoses that might trigger case management services could include cystic fibrosis, cerebral palsy, spina bifida, heart, respiratory and G.I. anomolies, fetal malnutrition and near drownings in addition to high risk infants. There are other diagnoses such as head and spinal cord injuries which have a high proportion of older primarily adolescent children.

In order to give you an idea of the involvement of case management in the case of chronically ill or injured children for Equicor, about 50% of the head injury cases and 25% of spinal cord's were dependent children. About 1,000 high risk infants are referred per year to case management and 34% of them will be chronically ill. For the year 1987, Equicor had some 2,500 case management referrals, 23% were dependent children. Of the 893 cases that were ultimately managed, 250 (28%) were dependent children.

We believe case management not only assures the individual high quality care but also economical care. The chronically ill/injured children managed by Equicor had an average expense of some $40,000 as opposed to an estimate expense without case management of some $90,000. A per case savings of $50,000.

Despite the generosity of current employer based plans, the out-of-pocket limits may be "catastrophic" for some working families at or near the federal poverty level. HIAA is cognizant of the hardship even modest deductibles might have on these families. We, therefore recommend expansion of the medically needy spend down program under Medicaid. Such expansion should be coordinated with employer plans and would supplement employer coverage for low income people. Such integration of employee plans and Medicaid would assure low income workers that their maximum out-of-pocket limit was in keeping with their total resources.

Individuals who exceed a policy's maximum benefits typically do so because of a severe, high cost, chronic condition. Sometimes private coverage is exhausted before the maximum benefit level is reached because private policies are designed to cover acute conditions, not long-term and custodial ones.

As recently as five years ago, only 16 insurance companies sold policies that covered long term primarily custodial care. Their market was exclusively the elderly. Since then, about 80 companies have entered the market and at least one-half million individual policies have been sold. Most recently, a number of companies have begun offering long-term care policies to employees, dependents and parents. The average age of purchasers of such employer sponsored policies is surprisingly about 40 years of age. Such long-term care policies would be appropriate for children with chronic impairments or traumatic injuries.

Some 35 million Americans are without either public or private health care coverage. Thirty-two percent of these are children. HIAA recently proposed a comprehensive plan for the uninsured. Under the plan, children would be covered as follows:

a) All children below the federal poverty level would be covered under Medicaid, regardless of the family relationships or the work status of adult family members. Currently, there are 4.3 million uninsured children below the poverty level, or 12 percent of the total uninsured population.

b) Children in families just above the federal poverty line would qualify for Medicaid after their family has spent down so called excess income on medical bills. HIAA also supports enactment of Medicaid spend down programs in all states.

c) We believe that all children regardless of the family's income level would be eligible for employer coverage of dependents, so long as a parent worked 20 hours or more per week. There are 8.3 million children, or 24 percent of the uninsured, falling under this category.

d) Children of those parents who are self-employed would be more likely to receive private coverage, if the self employed received a 100 percent, instead of the current 25 percent, tax deduction for themselves and their dependents. There are 860,300 uninsured children of the self-employed. They account for 2.5 percent of all the uninsured.

e) The only uninsured children for whom HIAA does not have a coverage proposal are those children of nonworkers with incomes above 200 percent of the federal poverty level. There are about 175,000 such children, accounting for less than 0.5 percent of the uninsured. Such non-poor families should have no problem purchasing individual policies.

f) Approximately 1 million Americans are considered medically uninsurable because of their existing health conditions. Some of these uninsurables are children. HIAA believes that health insurance should be made available to all uninsurable individuals, whether children or adults, through specifically created coverage mechanisms. One mechanism is state pools for high risk individuals not eligible for other coverage. Fifteen states currently have such pools. HIAA also proposes a second mechanism to re-insure employer groups who would otherwise be uninsurable.

To fulfill the private sector needs just outlined, insurers would develop low-cost prototype plans which have either basic benefits with low-cost sharing or more comprehensive benefits with higher cost sharing. All plans would limit out-of-pocket expenses and provide generous lifetime maximum benefits. Doing this, however, will require a federal preemption of state mandated benefit laws.

In order to meet the needs of poorer American children, the HIAA urges the speedy enactment of the Medicaid expansions we have enumerated today. This committee has before it several bills which would be a reasonable first step along the road to assuring everyone equal availability of care.

S. 2122, The Medicaid Infant Mortality Amendments of 1988 sponsored by Senator Bradley and co-sponsored by seven other members of this committee from both sides of the aisle deserves early consideration and has our full support. Unless we are able to give all poor women and their young children proper care, the uninsured gap will remain. More importantly any hope we have of closing the infant mortality gap will be seriously jeopardized. I believe there are other bills before you, which also deserve considerations, sponsored by Senators Durenberger and Chafee which also address these issues in whole or part.

Many of the states have taken up the challenge as well. Half currently provide Medicaid coverage to pregnant women and their children up to the poverty level. Fifteen have enacted state pools for uninsurables. Thirty-four have medically needy programs.

Mr. Chairman, the insurance industry is willing and anxious to move forward in helping to solve the problem of the uninsured, particularly children. We look forward to work with you and your colleagues on this committee.

STATEMENT OF

THE HONORABLE RAY MABUS
GOVERNOR OF MISSISSIPPI
on
HEARING ON CHILDREN'S HEALTH CARE

March 23, 1988

Good morning Mr. Chairman, and members of the committee. My name is Ray Mabus and I am Governor of the State of Mississippi. I appreciate the opportunity to testify today on behalf of the National Governors' Association regarding the efforts that the states have made to address the problem of infant mortality. I do not need to tell you that the infant mortality rate remains at an unacceptably high level throughout most of the country. However, I believe that the activities states have initiated with federal support over the past few years gives us reason for optimism.

I will not go into all of the statistics on infant mortality this morning. You have experts in this field scheduled to testify who can describe the incredible depth and breadth of the problem. However, I want to mention that the infant mortality rate has been particularly acute in the southern states. In my region of the country infant mortality is significantly higher than the national average. In 1985, the national average was 10.6 deaths for every 1,000 live births. In the south, the rate was 12.4 deaths per 1,000 live births.

Because of the magnitude of the problem in the southern states, former Governor Richard Riley of South Carolina and others in 1984 established the Southern Regional Task Force on Infant Mortality. The purpose of the Task Force is to educate state governments on the dimensions and causes of the problem and to formulate and recommend policies that states could use to effectively combat infant mortality.

The Task Force, through the able leadership of Governor Riley, developed several recommendations to improve the education, nutrition and health care of children and pregnant women. The most significant and far reaching proposal called for a revision of the Medicaid program to allow children and pregnant women whose income was at or below the federal poverty line to receive services paid for by Medicaid. The National Governors' Association (NGA) the adopted this recommendation as policy in 1986.

The adoption of this policy marked a significant departure from the NGA's previous Medicaid policy. This was the first time that the NGA embraced the idea that eligibility for Medicaid should be based on the income and assets of the individual only and not on other categorical requirements related to cash assistance programs. Rules and regulations which properly apply to direct cash payments should not hamper a person's access to health care. The governors feel strongly that this vulnerable population should be able to receive medical attention when it's needed.

For southern states, the link between cash assistance programs and medical assistance programs created an additional barrier to efforts to target and reach this group. Despite the fact that southern states receive a high rate of return from the federal government for state dollars spent, we could not afford to increase the level of cash assistance payments so that more people would be eligible for medical assistance.

Separating the Medicaid program from the cash assistance program made good economic sense. It allowed us to target our limited funds for the population where the dollars have their greatest impact. Each dollar spent on prenatal and infant care for a child saves many future dollars. Every child who is born healthy has the potential to become a tax payer rather than a tax consumer. The cost of providing preventive medical care is much less than paying for the chronic and lifelong problems that often result from low birth weight.

As decision makers, you know that many groups in our society have unmet needs, needs we would all like to address. But because of limited resources we have to set priorities. For governors, these needy women, infants and children are a top priority.

Because of this committee's leadership, the Omnibus Budget Reconciliation Act of 1986 included the NGA's proposals. This legislation gave states the option of expanding Medicaid eligibility to all pregnant women and infants, up to age one, whose family income is at or below the federal poverty level. States can also choose to impose limit on the assets a family may have. The Omnibus Budget Reconciliation Act (OBRA) of 1987 allows states to extend coverage to children up to age five with income at or below the poverty level, and to provide coverage to pregnant women and infants with income at or below 185 percent of the poverty level. The states welcomed these changes.

The states have effectively used the changes in the federal statutes in combination with outreach programs (at the state and local level) to effect major advancements in the way infant mortality is being addressed. Let me briefly summarize:

To date, thirty-one states have opted to provide Medicaid services to pregnant women and infants up to age one. At least four other states are covering the same population through their medically needy programs or with state dollars. Therefore, thirty-five states (including the District of Columbia) are providing the coverage envisioned by the committee when it adopted the eligibility option in 1986. Several more are expected to adopt this option during this year. Clearly, the states have acted swiftly to take advantage of this opportunity.

In the South, the response has been even more dramatic. Of the eighteen southern states (including the District of Columbia), sixteen are already providing coverage to pregnant women and infants. I am proud to say that almost all states in my region have adopted aggressive policies to fight infant mortality.

The states as a whole have responded positively in several ways to their options under Medicaid. Twenty-two of thirty-one states covering pregnant women and children have phased in older children as allowed by OBRA-86. Twenty-five of these states provide continuous eligibility to pregnant women regardless of fluctuations in their income. Finally, fifteen states provide Medicaid services to women immediately upon a determination of pregnancy rather than waiting for the normal eligibility process to be completed.

Let me assure you at this point that state and local efforts to combat infant mortality go beyond handing out Medicaid cards. Outreach programs are essential because access to appropriate care is still a problem even when financing is available. States have worked aggressively and innovatively in creating necessary outreach programs.

Allow me this opportunity to describe the critical situation in Mississippi and how we have moved to combat the problem. Until 1985, Mississippi consistently suffered the highest infant mortality rate of any state in the nation. In 1976, Mississippi's infant mortality rate was 42 percent higher than the national average. Since 1985, Mississippi has moved from 50th in the nation to 47th. The infant mortality rate has been reduced from 21.6 deaths per 1,000 live births in 1976 to 12.3 deaths per 1,000 live births in 1986.

By all calculations, these are steps in the right direction. And what they measure is the saving of lives, the prevention of disabilities, and the unlimited possibilities that are open to babies born healthy.

We have moved ahead by making the best use possible of the Medicaid Program. First, we expanded our Medicaid coverage to include the married poor, before it became a federal mandate. Then, we broadened our standard of need for eligibility to 50 percent of the poverty level. Under the OBRA-86 option, we were among the very first states to move eligibility standards to 100 percent of poverty.

These combined efforts are expected to provide coverage for at least 7,000 more pregnant women and 46,000 more children when fully implemented. Our state legislature is currently considering taking advantage of the most recent Medicaid expansion for pregnant women and infants to 185% of the poverty level and implementing case management services for high risk Medicaid maternity patients.

In addition to Medicaid expansion, we have instituted other creative means of stretching our limited resources.

Mississippi is fortunate to have a statewide system of public health departments, with services provided in every county. More than 40% of the pregnant women in the state (17,000) are served in this system. In recent years, the state legislature has consistently increased funding for the health department for its maternity program, not only to provide prenatal care but to engage the services of physicians in private practice to ensure continuity of care when time for delivery arrives.

In addition, Mississippi prudently uses other federal monies targeted for pregnant women and children.

The MCH Block Grant, through which Mississippi receives $7 million, enables the health department to provide prenatal care and delivery services to low income women.

The WIC program in Mississippi serves the highest percentage of persons eligible for WIC in the region. The number of infants served is equivalent to 60% of all live births in the state.

With $3 million in family planning funds, Mississippi provides services to 100,000 women in the state, one-third of whom are 20 years of age or younger.

A SPRANS (special project of regional and national significance) grant from the Public Health Service some five years ago permitted the hiring of a perinatal outreach nurse to receive referral calls to the state operated hotline from women experiencing problems with access to medical care. Significant statewide promotion through posters, flyers, and television and radio spots let providers and consumers know of the availability of the toll free number for this purpose. It continues to be funded through a Post-neonatal Death Impact Project SPRANS grant. Case studies of these calls are reviewed every two weeks by a Medical Access Task Force and have become the basis for legislative and public policy action to close gaps in the system.

Mississippians are proud of our state's improvement in infant mortality. However, we cannot afford to relax our efforts since we still have a long way to go. In 1986, of 41,868 births in Mississippi, 342 women still receive no prenatal care at all, and an additional 9,600 women receive no care until after the first trimester of pregnancy. Furthermore, the infant mortality rate for non-whites is still almost twice the rate for whites, and the percentage of births which are low birth weight remains relatively unchanged. Continued support of cost-effective services to prevent unplanned pregnancies, especially to teenagers, and to ensure that children are born healthy and nourished properly is essential to the future of our state.

Despite Mississippi's efforts, there is no doubt that more can be done. The NGA believes that states should be given the option to provide Medicaid services to all children under the age of 18 whose family income is at or below the federal poverty level.

We believe strongly that Congress should continue its efforts to use Medicaid to finance efforts to decrease infant mortality and improve the health of all low-income and disadvantaged children. We have strongly supported this committee's efforts to make Medicaid funds available and to grant states the flexibility to tailor Medicaid programs to each states specific needs. Further expansion of the options already in place will further promote state efforts on behalf of pregnant women and children.

Thank you for giving me the opportunity to testify before you today. I would be happy to answer any questions you might have.

STATEMENT OF U. S. SENATOR SPARK MATSUNAGA BEFORE THE HEARING ON CHILDREN'S HEALTH CARE

Senate Finance Committee
SD-215 Dirksen Senate Office Building
Washington, D. C.
Wednesday, March 23, 1988 - 10:00 a.m.

Mr. Chairman, at the outset, I would like to express my appreciation to you for holding these series of hearings on children's health care issues -- a vital, but often-ignored area of concern. I would also like to take this opportunity to commend the Chairman for his leadership in establishing the National Commission on Children which will hold public hearings and make recommendations to Congress on how to protect and enhance the physical, mental, and emotional well-being of children and youth.

As a cosponsor of the bill introduced by Senator John Chafee, S. 1537, which aims to reduce the immense financial burdens on families with children who have a catastrophic illness, I look forward reviewing the testimony of the witnesses before us today.

Mr. Chairman, my state of Hawaii, while idyllic in climate and natural surroundings, also faces problems in children's health care. In Hawaii, the Kapiolani Medical Center for Women and Children provides care for nearly all of the newborns, infants, and children with catastrophic illnesses in the state as well as from many of the Pacific Island territories. Mr. Richard Davi, President of the Kapiolani Medical Center informed me that during Fiscal Year 1987, 67 children under the age of one were discharged from his facility with hospital bills in excess of $50,000. The bills ranged from $50,000 to $400,000. Excluded from this group were children who "lived" at the Medical Center throughout the year. As you know, for long-term, ventilator-dependent children, hospital bills for their years of care far exceed $400,000. I need not tell everyone here that the consequences for the families are devastating. My Chairman, I request that these case studies be entered into the hearing record.

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Case 1: Baby Dawn

Baby Dawn was born severely premature at 24 weeks gestation. At birth, she weighed approximately 605 grams which is 1 lb. 5-1/2 ozs. She is the third child of a 33-year-old mother and 34-year-old father. Shortly after birth, she was rushed up to the Neonatal Intensive Care Unit where she has remained for the past six months.

Prior to baby's birth, Mrs. Black began having complications and was required to remain in bed until delivery. She was forced to quit her job, and the family was required to make ends meet on Mr. Black's salary.

Mr. and Mrs. Black had hoped to purchase a home for their family. Just prior to baby's birth, Mr. Black had begun arrangements to finalize such a purchase. Unfortunately, they were unable to do so as it became apparent that they could no longer afford to. Although this family qualifies for medical coverage under Mr. Black's policy, their current medical expenses since Baby Dawn's birth are $275,000. Their share of the expenses is $19,000. Doctors are unable to determine baby's length of stay, and therefore, it is possible that the medical expenses may double.

Due to the obvious financial strain and continued emotional hardships, Mr. and Mrs. Black have grown apart from each other. The birth of Baby Dawn has compromised this family's ability to function as a whole unit. Coping mechanisms have been severely compromised and parents have found it increasingly difficult to communicate with each other, and therefore, are unable to support each other.

Case 2: Baby David

David was born prematurely on Lanai, but at two weeks of life was admitted to our PICU for pneumonia, congestive heart failure, PDA and prematurity. His young parents have three other children. The father works periodically for the pineapple industry, and mother is unemployed. They have been denied (medicaid) DSSH. David has been in our PICU since May 27 and recently underwent cardiac surgery. His parents have an extremely difficult time finding enough resources to pay for plane fare to visit David and so visit very infrequently. Each round trip is about $100 for them. David's current stay is indeterminate due to the critical nature of his illness. It is also anticipated that he will have ongoing repeat hospitalizations. As of mid-August, his hospital bill was $169,000.

Case 3: Keoki

Keoki is an 8-month-old child who has spent most of his life at Kapiolani Medical Center. He was an NICU patient for five months prior to discharge to his home on Molokai. After a very brief stay, he was readmitted to PICU in May for severe bronchial pulmonary dysplasia and respiratory failure. His young mother has another child and is supported by (AFDC/medicaid) DSSH. However, DSSH will provide plane fare and accommodations at the Ronald McDonald House only at the time of admission and discharge. Since she is not employed, she finds it very difficult to gather funds to visit Keoki. Each round trip and a few days at the Ronald McDonald House costs her about $100. Keoki's stay at KMC will be indeterminate due to the critical nature of his illness. It is also likely that Keoki may have repeat hospitalizations once discharged. As of mid-August, his hospital bills exceeded $125,000.

TESTIMONY BEFORE THE
SENATE FINANCE COMMITTEE
U.S. CONGRESS

PRESENTED BY
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MARCH 23, 1988

TESTIMONY

Mr. Chairman and members of the Committee, I am pleased to appear before you today to discuss the health care needs of chronically ill and disabled children. For the last five years I have been engaged in research concerning trends in the size of this population, their use of health care services, and expenditures for services. Much of my testimony this morning draws upon that work.

Few children in the U.S. experience lasting or major illnesses during childhood. The vast majority enjoy a healthy childhood; the bulk of health services provided to them is for preventive care and routine treatment of minor acute conditions. Expenditures for health care are consequently minimal for most children. Indeed, annual health care expenditures for children average less than half of those for working age adults and are only about one-fifth of those for the elderly.

Averages can mask substantial differences among individuals, however, and there exists enormous variation in child health care utilization and expenditures. A relatively small proportion of children accounts for a large share of total health care expenditures. For example, nearly one-fourth of all children less than 18 years old do not see a physician during the course of a year, yet the 10 percent of children with the highest use levels account for nearly one-half of all physician services provided to children. Similar patterns of disproportionate use exist for most other major health care services, including hospital care and services provided by allied health professionals. Without adequate insurance or other financial means, meeting expenses for these services can impose tremendous financial burdens on families of sick children.

Although only about 1 in 20 children is hospitalized each year, most children with high health care expenditures have spent some time in the hospital. About two-thirds of children with hospital episodes are treated for acute health problems. Once treated, they generally experience minimal need for ongoing expensive medical care services. The remaining children are hospitalized for chronic health problems and differ from acutely ill children in that their needs for medical services usually extend well beyond a single hospitalization. For example, a child with a severe and degenerative chronic illness such as cystic fibrosis may be hospitalized several times over a shortened but indefinite lifespan.

Prevalence of Chronic Illness

Although there is no universally accepted definition of chronic illness, most experts agree that a chronic condition is one that extends over a long time period. Chronic illness can affect a child's ability to function in age and developmentally appropriate roles. Among children there is wide variation in the prevalence, severity, duration and age of onset of chronic conditions.

Using the National Center for Health Statistics' convention of defining conditions as chronic if they have been present more than three months, or conditions that ordinarily have a duration of more than three months such as arthritis or diabetes, approximately 30 percent of all children under age 18 are affected by chronic physical or mental conditions. Data from the National Health Interview Survey suggest that only a small proportion of these children are so severely affected as to need prolonged and expensive treatment. In fact five of every six children with chronic conditions experience no limitations in their usual activities. A substantial proportion of these mild chronic conditions such as allergies, skin problems, and minor respiratory diseases are outgrown as children mature.

The remaining chronically ill children are of much greater concern from a health viewpoint. These children, who number 3.3 million and account for 5 percent of the population under 18, suffer some degree of disability because of their chronic illness. About 30 percent of the children in this group, or slightly less than 1 million, are limited in their ability to participate in minor activities, such as sports and recreational pursuits. Another 2 million children are more severely limited by chronic illness and are restricted in the kind or amount of their major activities such as school for school-age children and play for preschool-age children. At the most severe end of the spectrum are children who are unable to engage in any major childhood activities. Nationwide, approximately 400,000 children, including about 100,000 residing in institutions, fit into this category. Also within this category are several thousand children who are dependent on some form of life sustaining technology.

Disabled children are afflicted by a variety of chronic conditions. Mental retardation and asthma are the most common causes of disability for children, but learning disabilities, orthopedic impairments, and vision, hearing and speech problems are also common among disabled children residing in the community. While much less is known about disabled children residing in institutional settings, it appears that most suffer from multiple physical and mental disabilities.

Health Care Utilization by Disabled Children

Children with chronic conditions severe enough to result in disability experience medical and social service needs greater than those of other children. The needs of individual children vary greatly depending on diagnosis and severity but in almost all cases they include basic ambulatory and hospital care and case management services. In addition, with more severe disabilities children may require physical and other therapies, mental health services, durable medical equipment and appliances, and home health care.

Most children with disabling chronic illnesses use health services on an intermittent basis, often following acute flare-ups of their chronic conditions, and they use fewer services during periods of remission. On the other hand, disabled children who are consistently high users of medical and social services are much more likely to require care in an institutional setting. Unfortunately, little is known about patterns of service use for institutionalized children since they are usually excluded from national health surveys. Similarly, data is lacking on the use of highly specialized equipment such as dialysis machines and respiratory ventilators required by severely disabled children in the home setting. The problem is that what is known about use patterns of disabled children comes from national surveys designed to measure service use for the population as a whole and not the special needs of chronically ill children. As a result, existing estimates greatly understate actual use of medical and social services by disabled children.

The limited national data that are available show large differences in use of health care services by disabled and nondisabled children. According to the National Health Interview Survey, disabled children are three times more likely to be hospitalized as nondisabled children. Once admitted they stay twice as long as nondisabled hospitalized children. The result is that the 5 percent of children with disabling chronic conditions account for 31 percent of all hospital days for the noninstitutionalized population under age 18. The most severely disabled children, those unable to attend school or engage in ordinary play, spend an average of 40 times as many days in the hospital each year as their nondisabled counterparts.

Professional services are also used disproportionately by disabled children. Disabled children under 18 have an average of 11 physician contacts annually, compared to an average of less than 4 for other children. Data from other national surveys indicate use of nonphysician professional services, such as those provided by physical therapists, nurses, psychologists and others, is nearly six times greater for disabled children. Disabled children are reported to use twice the number of prescribed medications as other children and are at least twice as likely to make use of vision aids and hearing devices, orthopedic appliances, and medical transportation services.

Overall, disabled children use at least twice as many health services as nondisabled children. For inpatient hospital services and for services provided by nonphysician professionals the differences are much greater. Were data available on other health related items used principally by disabled children such as durable medical equipment, home renovation, expendable medical supplies and institutional care, the differences in resource use would appear much more dramatic.

The cost of this care is substantial, and most families of disabled children can expect to face recurring expenditures year after year. Unfortunately, no current data are available to accurately estimate the financial burden of disabling chronic illness. Data collected in the 1980 National Medical Care Utilization and Expenditure Survey indicate that total nondental medical charges for noninstitutionalized disabled children under 21 years old were nearly three times higher than those for nondisabled children. In 1986 dollars this translates to an average of $1,242 per disabled child and $430 for each nondisabled child. However, because many services used principally by disabled chidlren were not included in the survey, the true financial burden, both in relative and absolute terms, is much greater. Results from this same survey also indicate that expenditures were unevenly distributed among disabled children with a small proportion accounting for a large share of total expenditures. Indeed, when ranked according to expenditures, the upper 10 percent of disabled children--those with charges exceeding $3,000 in 1986 dollars--accounted for 65 percent of all charges for the disabled population. Hence, a small segment of the disabled population, principally those who have been hospitalized, accumulate very high charges, while most disabled children accumulate comparatively modest bills, primarily for ambulatory care services.

Paying for Health Care Services

Families of disabled children rely on a variety of sources for covering their medical care bills. On average, families of disabled children pay about one-fifth of their children's medical care bills directly out-of-pocket. The remaining expenses are met through a variety of third parties. Six of every seven disabled children have some form of private or public insurance coverage. For most disabled children, private health insurance is the primary source of payment for medical care bills. Approximately 65 percent of disabled children have some form of private health insurance. For the most part this insurance is group coverage obtained through parental employment. Individually purchased policies cover few disabled children because these plans often contain restrictions on services covered and frequently exclude coverage of preexisting conditions. In contrast, group policies usually include more generous benefits and, if obtained through employment, rarely contain exclusions for preexisting conditions.

Still, what services a child is entitled to and the share of the bill met by the insurer or employer varies enormously from plan to plan. Standard group insurance usually provides adequate benefits for hospital care, physician services and other basic medical services. Yet some have raised concerns about the adequacy of coverage for many home services and ancillary therapies that disabled children may need.

In addition to limits on covered services, the degree to which families of disabled children are protected against high out-of-pocket expenses will depend on several other characteristics of their insurance including:

- **Deductibles:** the amount the family pays before insurance begins paying
- **Coinsurance:** the share of charges paid by the family after the deductible has been met
- **Maximum Benefit Levels:** insurers may impose a dollar ceiling on a per illness, per year, or lifetime basis
- **Limits on Out-of-Pocket Liability:** many insurers establish a limit on family expenses after which the insurer usually pays for benefits in full.

Overall, private health insurance appears to provide adequate financial protection for families of disabled children whose needs are limited to basic hospital and physician services. These services are fairly well-covered by most private health insurance plans. However, for severely disabled children with intensive service needs, especially for home care services, private health insurance may not provide adequate financial protection and, consequently, may limit access to needed services.

Because private health insurance is usually obtained by parents through the workplace, private health insurance is much more common among higher income households. Disabled children living in families with incomes above the poverty level are nearly four times more likely to be covered by private health insurance than similar children in families with incomes below the poverty level. Indeed, only one in every five disabled children from impoverished families is covered by private health insurance.

Disabled children without private health insurance are sometimes eligible for public insurance coverage. Approximately 24 percent of disabled children are covered by some form of public coverage including Medicaid, Medicare, CHAMPUS and other public sector programs. Four out of every five disabled children with public coverage are covered by Medicaid. Eligibility for this program is generally connected to the Aid to Families with Dependent Children and Supplemental Security Income programs. Financial eligibility thresholds under these programs vary from state to state and many low income disabled children are ineligible because their family incomes are slightly above the state set limits. Survey data indicate that only 59 percent of disabled children living in families below the poverty level are covered by Medicaid.

State Medicaid programs are required to provide a basic service package that includes, among other services, hospital and physician care. However, many states impose limits on these basic services which can create severe hardships for low income families. An additional problem for families with Medicaid coverage is finding providers who will accept Medicaid's generally low provider payment levels. While Medicaid is subject to many criticisms, one important and major advantage of Medicaid to low income families is that deductibles and copayments are very low or nonexistent in most states. Hence, despite its drawbacks, Medicaid plays an important role in financing the health care needs of many low income disabled children.

Many families can also turn to the state and federally funded programs for Children with Special Health Care Needs (formerly known as the Crippled Children Service programs). These programs provide case management and other critical health services to eligible chronically ill children. Each state sets its own eligibility criteria, and there is tremendous variation in the types of children eligible based on diagnosis and financial status as well as the services offered. Because of state-to-state variability in eligibility criteria, a disabled child may be ineligible for Medicaid and CCS in one state but eligible for both programs in another.

At any given point in time approximately 86 percent of disabled children have some type of private and/or public insurance coverage, but 14 percent, or nearly one-half million disabled children, are without any form of health insurance. When viewed over the course of an entire year, up to one-fourth of all disabled children may be without coverage at one time or another. Clearly, the absence of coverage exposes families to tremendous financial risks and can pose substantial barriers to obtaining needed services.

According to the National Health Interview Survey the primary reasons for an absence of health insurance coverage are financial. Families of seven of every ten uninsured disabled children said the main reason for their lack of coverage was that insurance is simply too expensive. The next leading reason cited was loss of coverage attendant to loss of employment. Given these reasons for lack of health insurance, it is not surprising that disabled children living in families with incomes below the poverty level are twice as likely to be uninsured as disabled children from more affluent families.

Conclusion

Chronic illness varies in its impact on children's health and functional status. The result is that use of health care and expenditures vary greatly from child to child. In some cases expenses are predictable, but more often they are not. The available evidence suggests that families are unevenly exposed to financial risks associated with chronic illness. Higher income families tend to be well insured and appear capable of meeting most health care expenses not covered by insurance. Moderate and low income families are in a much different position. They are much more likely to be uninsured or underinsured and have less financial resources to draw upon in meeting health care bills not covered by insurance. Working poor families may be the most financially vulnerable of all. Without employer provided health insurance and with incomes above Medicaid eligibility thresholds, these families can face tremendous difficulties in meeting health care expenses for their disabled children.

Adequate health insurance coverage should be available to families of all disabled children. The current patchwork of public and private programs falls short of reaching this ideal. Avenues toward achieving this goal include expanding Medicaid coverage, increasing appropriations for the Maternal and Child Health block grant, and encouraging employers to provide at least minimal health insurance benefits to their employees and dependents. Were resources available, perhaps the most desirable approach to meeting the needs of this population would be to establish a national catastrophic health insurance program for disabled children. Doing so would greatly diminish existing inequities and could ensure that all disabled children receive adequate and appropriate care.

TESTIMONY
OF
BLUE CROSS AND BLUE SHIELD ASSOCIATION
ON
CHILDREN'S HEALTH CARE ISSUES

BY

DOUGLAS S. PETERS
SENIOR VICE PRESIDENT

MARCH 23, 1988

Mr. Chairman, Members of the Committee, I am Douglas Peters, Senior Vice President of the Blue Cross and Blue Shield Association. We appreciate this opportunity to offer our perspective on some of the issues related to health insurance coverage for children.

As the largest health benefits system in the country, covering nearly 80 million Americans in our private business, we are deeply committed to health benefits protection for our nation's children.

We want to present two aspects of this issue as you begin your deliberations:

- First, a review of what Blue Cross and Blue Shield Plans are doing to extend health coverage to children, including some of the innovative new programs that our Plans have developed for children;
- Second, some recommendations for action. While insurers are actively engaged in increasing health coverage of children, the private sector alone cannot overcome all financial barriers to health insurance coverage. The scope of this problem indicates that improved health coverage for children requires a joint private-public effort.

Blue Cross and Blue Shield Coverage and Benefits

Our 77 member Blue Cross and Blue Shield Plans across the country have long been known as providers of comprehensive health benefits. Our Plans cover over 16 million families, including some 21 million children, usually through employment-based benefit programs.

We believe that your deliberations call for an understanding of four key areas in our health coverage for children:

- Coverage of children as dependents;
- Benefits offered;
- Cost-sharing requirements; and
- Special programs available for children and families.

The following sections provide information on what Blue Cross and Blue Shield Plans are doing in each of those areas.

Coverage of Children as Dependents. Blue Cross and Blue Shield Plans cover over 21 million children. Typically, newborn children are covered at birth and are added to the policy regardless of the child's medical condition. Even policies that do not include dependent coverage typically provide coverage for the newborn child for a specified period (usually 30 days), during which family coverage can be purchased.

One of the key problems that we see in the benefits market affecting children today is the lack of dependent coverage, with an employer contribution, through the employment group. Employers may make contributions toward their employees' health insurance coverage, but contributions are less likely for dependent coverage.

Unfortunately, we do not have comprehensive data on many of the questions you may have about marketplace practices in each of our Plan areas. However, a recent survey of our small group market — those with 25 or fewer employees — does provide some specific information on practices by small employers, including the extent of dependent coverage. Fifty-one Plans, or two-thirds of the Blue Cross and Blue Shield organizations responded to this survey.

According to the survey, over two-thirds of the respondents estimated that small employers cover over 80 percent of the cost of employee coverage. However, nearly 50 percent of small group employers do not contribute, at all, to dependent coverage.

The high cost of dependent coverage was the major reason given for the lack of contributions by small employers for this coverage. In reviewing the data from this survey — which we will refer to several times throughout our testimony — it is important to note that large employers generally offer more comprehensive benefits than smaller employers.

Benefits. Benefit packages for individuals and families covered by Blue Cross and Blue Shield Plans tend to vary according to the number of employees in the group. Large employment groups generally tailor the benefits that are offered to their employees, while smaller groups generally choose from among a number of alternative coverage packages. In general, the typical product for an employment-based group covers a comprehensive range of services including: inpatient and outpatient hospital, physician surgical/medical, outpatient diagnostic, outpatient therapies, psychiatric care, emergency care, maternity care, and home care. Some of the most commonly offered and purchased optional benefits include prescription drugs, dental care and hospice care.

With regard to pre-natal and well baby care, seventy percent of our Plans report that the coverage most commonly purchased by small groups includes coverage for routine pre-natal care. Over one third report well-baby care being covered in the most frequently purchased coverage. Such coverage is more likely to be provided by large employers, who tend to offer more comprehensive benefits to their employees.

In reviewing the benefits offered by Blue Cross and Blue Shield Plans, it is worth noting a relatively new program — individual case management — used by many of our Plans that can result in children and others receiving special benefits that may not be covered under their policy. Individual case management is an organized effort to: identify patients who have the potential to be high cost, long stay and/or complicated cases; locate and make available to the patient medically appropriate settings; and manage their health care benefits as cost effectively as possible. This may include providing benefits when necessary that are not covered under the terms of the contract. For example, if a child's coverage did not include home care services, but the case manager recommended home care as an alternative to costly hospitalization, those services could be covered under the policy.

These programs are increasingly being incorporated by Blue Cross and Blue Shield Plans as a means of stretching coverage and assuring care in the most appropriate and cost-effective setting for those with long-term, and often catastrophic, health problems. To date, 70 percent of our Plans have developed case management programs as part of their managed care products.

Cost Sharing. As with benefit coverage, cost-sharing requirements generally are tailored to meet the needs of larger employee groups. Small groups generally choose from cost sharing alternatives which include options for deductibles, out-of-pocket maximums, and lifetime limits on benefit payments.

A deductible is the amount that individuals must pay each year for covered benefits before payment under the policy begins. For the most commonly purchased small group offerings, deductibles for single coverage tend to be less than $200 (62 percent of Plans), while deductibles for family coverage range from zero to $1,000.

The maximum annual out-of-pocket liability for deductibles and coinsurance is generally set at $1,000 or less for individuals for our small groups. Once an individual spends that amount on deductibles and coinsurance for covered benefits, the insurer begins paying for 100 percent of covered benefits. Maximum out-of-pocket liability for families is generally two times the amount for individuals.

The lifetime maximum defines the extent of an insurer's total benefit payment for an individual or family. Some small group products include no such lifetime maximums. In other words, the policy will pay unlimited benefits. More commonly, these products include a maximum of one million dollars or more. Few individuals or families ever meet this lifetime maximum.

BSBC Special Products for Children. In addition to our regular products, many Blue Cross and Blue Shield Plans have developed innovative products especially designed for children who for financial reasons lack access to important preventive and primary care health services.

1) Children in Low Income Families. In 1985, Blue Cross of Western Pennsylvania and Pennsylvania Blue Shield, in recognition of the number of unemployed and marginally employed people in the state, created the Caring Program for Children.

The Caring Program offers primary health care coverage to children who are not eligible for Medicaid but whose parents cannot afford health insurance. Since its inception, nearly 8,000 children have received primary preventive and emergency health care service coverage at no cost to their families. Benefits include full coverage for emergency outpatient and medical care, minor surgery and diagnostic tests, outpatient surgery, emergency accident care, pediatric preventative health maintenance, and unlimited medically necessary physician office visits and diagnostic tests.

Through contributions of $13 a month, foundations, businesses, unions, individuals, and civic and religious organizations are able to sponsor children regardless of their medical condition. Blue Cross of Western Pennsylvania [redacted] matches every contribution, dollar for dollar, thus enrolling two children for every one sponsored by a public contribution. The Plan [redacted] has further expressed its [redacted] commitment to these children by subsidizing the administrative costs of the program so that nearly every dollar contributed goes directly towards providing health coverage to a needy child.

A number of other Blue Cross and Blue Shield Plans also have developed similar programs including Plans in Missouri, Maryland, Alabama, and North Carolina.

2) Pre-Natal Care. In an effort to reduce infant mortality and morbidity rates, Blue Cross and Blue Shield Plans recently joined forces with the March of Dimes and radio and television companies to develop such comprehensive programs as "Beautiful Babies" sponsored by Blue Cross and Blues Shield of the National Capital Area and "Baby Your Baby" sponsored by Blue Cross and Blue Shield of Utah. These programs rely on massive public information and awareness campaigns to educate the public on the importance of pre-natal care and to encourage expectant mothers to visit their doctors early in their pregnancies. One of the most important intended outcomes of the program is to identify high risk pregnancies as soon as possible.

One important component of these programs is the use of valuable coupon incentive booklets. These coupons are valid only when women visit their health care providers. The booklets include hundreds of dollars worth of goods and services designed to provide support during the woman's pregnancy and to improve her child's first year of life. Coupon items include prenatal vitamins, baby formula, transportation to check-ups and maternity and children's clothes. Support services include: a telephone hotline; a mother's network for support; and advice and access to smoking, alcohol and drug treatment.

In its first year, Blue Cross and Blue Shield of the National Capital Area distributed over 44,000 booklets, reaching two-thirds of all pregnant women in the Washington D.C. area.

"Beautiful Babies" has more than succeeded in reaching its goals of increasing awareness of the need for and providing incentives to obtain pre-natal care. Coverage of this program by local radio and television stations has spurred local governments into making free pre-natal care more accessible to low income women. Clinics are reporting an increase in visits as well as a visible use of the coupon book.

This program, initially established as an 18-month project, has been renewed for 1988 with even more ambitious goals.

3) The Unemployed and Marginally Employed: In a cooperative effort with the Kansas Medical Society, the Kansas Hospital Association and other health care providers, Blue Cross and Blue Shield of Kansas began a pilot program in January 1988 to provide health benefits for the state's unemployed and marginally employed. This program is designed to provide benefits to individuals and families who are low income and are not covered by group insurance plans or by state or federal health care programs. Applicants must: a) meet income eligibility limits of $8,000 per year for single persons or $15,000 for families; b) not be employed full time; and c) be under age 65.

Monthly premiums are based on subscriber age and begin as low as $17.35 (single) and $38.58 (family). Family coverage includes dependent children up to age 23. Handicapped, unmarried dependent children are covered over age 23 if the child became handicapped while enrolled. Area churches and philanthropic groups are being encouraged to contribute toward the cost of the premiums for needy individuals and families.

Covered benefits under this program include: inpatient and outpatient hospital services, medical and surgical services, emergency care, maternity and newborn care under a family contract, and care for nervous and mental conditions. Deductibles for a 12-month contract period are $1,000 for individual and $2,000 for families; however, health care providers who participate in the program assume responsibility for half of the deductible.

4) Temporary Coverage. Several Blue Cross and Blue Shield Plans have developed short-term products for those who face temporary periods without health coverage because of a job change, layoff, strike or other circumstance that might interrupt coverage. For example, Blue Cross of Washington and Alaska offers short term protection against costly medical bills at rates as low as $30 a month. There is no deductible, and the program will pay 80 percent of the first $5,000 of covered expenses up to a maximum of $250,000.

Coverage can be obtained for periods of 30, 60, 90, 120, or 180 days. Services include inpatient hospital care, including intensive and coronary care, surgical care, outpatient hospital services, emergency room treatment, emergency ambulance service and physician services. This product also includes benefits for necessary medical supplies, prosthetics, inpatient rehabilitative care and home health care.

Recommendations for Action

We are proud of these efforts to extend coverage to children, and Blue Cross and Blue Shield Plans will continue to do everything possible to extend coverage to children — and others — who are currently without health coverage. However, our successes in these areas are measured in the thousands of children — for a problem that is faced by millions. It is hard to imagine a national priority more important than improving health coverage for children, and we believe that reaching all children will require the type of joint public-private effort that is the cornerstone of our health care system.

We believe that the report by the Congress of the United States, Office of Technology Assessment, Healthy Children: Investing in the Future, provides an effective starting point for discussion. The Blue Cross and Blue Shield Association recommends that the Committee consider the options offered in the report with respect to improving Medicaid coverage and equalizing tax treatment for health benefits expenses.

Medicaid Improvements. Congress already has started to provide states with the option of expanding Medicaid assistance for low income pregnant women and their children. We believe that the Congress should consider requiring the states to cover pregnant women under Medicaid and to phase in coverage of children, starting with infants, up to the poverty level, as suggested by a number of bills that are before this Committee. In addition, for lower income workers, we believe that some form of Medicaid buy-in, should be considered for employees and dependents.

Equalizing Tax Treatment. Second, we believe that, in order to enhance coverage in the private market, Congress should provide the same 100 percent tax deduction for health benefit expenses for unincorporated businesses, sole proprietorships, self-employed, and individuals as is permitted for corporations.

Catastrophic Mandates. We recognize the need for catastrophic coverage for children and, as we noted earlier, Blue Cross and Blue Shield products are quite comprehensive. However, we are concerned that mandating inclusion of catastrophic benefits in all health insurance products might result in erosion of employer financial support of dependent coverage, which is the very problem that is of concern.

In summary, the Blue Cross and Blue Shield Association will continue to do everything possible in the private sector to extend coverage to children, through our regular policies and new and innovative programs for children. At the same time, we strongly support federal efforts to expand benefits for those we cannot reach, and look forward to working with the Committee as you begin to develop legislation.

0788M

STATEMENT FOR FINANCE COMMITTEE HEARING ON CHILDREN'S HEALTH CARE
SENATOR JOHN D. ROCKEFELLER IV
March 23, 1988

This is not a cheerful subject. Something is very wrong when a country as strong and wealthy as ours ranks 19th in infant mortality -- out of the 20 most industrialized nations. This is especially depressing when we recall that the United States ranked 6th in the mid-1950s.

We are slipping. A recent survey released by the federal Department of Health and Human Services reported that efforts to reduce the rate of infant deaths in America have stagnated. Some of our country's largest cities have recently experienced sharp increases in infant mortality. More low birth weight babies are being born -- infants who are at the greatest risk of dying or suffering lifelong disabilities. Twenty-four percent of all mothers in this country did not receive prenatal care in the critical first trimester of their pregnancy.

My state of West Virginia reflects these same depressing trends. When I was Governor, I initiated a major campaign to reduce teenage pregnancy and infant mortality. We were tremendously proud of our progress. Unfortunately, over the past several years, the progress seems to have halted. It is not difficult to explain why. As GAO found out in a multi-state study of maternal and child health, only about half of poor pregnant women in West Virginia receive medical care and attention during their pregnancy.

In my view, we can't allow these trends to continue. We not only have a moral obligation to protect our children, we must face up to the economic consequences of our current course. How can we prosper and compete if we squander so many of our children -- children who, if brought into the world healthy and if cared for when growing up, would fully contribute to America's future and security.

Today, we begin the process of taking stock of the condition of America's children and determining how to improve their health and wellbeing. It is no mystery that funding is central to turning these trends around. I believe we can obtain the support of the American people to invest far more resources and attention in our children. We certainly can't afford to continue neglecting them.

STATEMENT OF

DR. WILLIAM L. ROPER

ADMINISTRATOR

HEALTH CARE FINANCING ADMINISTRATION

MARCH 23, 1988

Mr. Chairman and Members of the Committee, I am Dr. William L. Roper, Administrator of the Health Care Financing Administration (HCFA).

I am pleased to be here this morning to discuss with you a subject that as a pediatrician is near and dear to my heart -- health care for children. Quality health care in the formative years is important for proper growth and development which are so crucial for getting a good start in life.

I am aware of the Chairman's recent initiative to establish a National Commission on Children and his interest in addressing the problems of children's access to health care. I would note that other members of this committee have sponsored legislation relating to various aspects of children's health care.

As Administrator of the Health Care Financing Administration, I oversee the Medicaid and Medicare programs which pay for health care for approximately 11 million children in our nation. The Medicaid program is the primary source of health care for the most vulnerable of our children -- those who are poor and disabled.

I can report to you this morning that the Medicaid program is serving the needs of all of its recipients in essential and innovative ways.

For a good part of its history the Medicaid program was linked to the receipt of welfare benefits. Recent Congressional action has removed that link for some groups of recipients. States now have the option of providing Medicaid coverage for pregnant women and for certain children who are not AFDC eligible because their income exceeds the States standard. These new options extend the possibility of Medicaid to many above the poverty line.

Because Medicaid is a State-operated program, the real story is how States in the face of new diseases, complex care needs, and fiscal problems are meeting the challenge of caring for low-income children.

Increasingly, State Medicaid agencies, Maternal & Child Health agencies, Women, Infants, and Children Supplemental Nutrition (WIC) programs, health departments and local health clinics are sharing fiscal and personnel resources to enhance their efforts and expenditures. Interprogram coordination works especially well for the provision of comprehensive, case-managed care to special populations such as disabled children and high risk pregnant women.

We, at HCFA, are encouraging States to increase their cooperative efforts. We created a Maternal and Child Health Technical Assistance Group -- made up of Medicaid and Maternal and Child Health directors -- which meets periodically to foster cooperation between the two programs. Besides just making good sense, improved cooperation leads to improved health care for Medicaid recipients. Together with the recent expansion in eligibility, this cooperation enables State Medicaid agencies to serve more people more effectively.

Pregnant Women and Children

Today, perhaps more than ever before, we realize that a healthy start in life requires good prenatal care. Poor prenatal care, and prenatal care begun late in the pregnancy, have been correlated with low birthweight babies who are more likely to have significant health problems and are in greater jeopardy of dying. Therefore, early access to quality prenatal care is a critical issue.

States have made major progress toward improved access to prenatal care by streamlining the Medicaid application process and expanding coverage of women in poverty. Twenty States are covering pregnant women up to 100 percent of the federal poverty line. Another twenty-three States are considering this optional coverage category -- that would bring us up to 43 States providing coverage to women with incomes at or near $11,650 in a family of four.

Several States are considering the new option provided by the Omnibus Budget Reconciliation Act of 1987, which allows States to cover women up to 185 percent of poverty, or $21,500 for a family of four. As many as seven States may select this option in the coming year.

Quicker access to prenatal care is being achieved through States' adoption of presumptive eligibility, a policy which allows a pregnant woman who appears to meet Medicaid eligibility requirements to be covered from the moment she walks into an approved provider's office seeking care. Under this coverage option, the State guarantees approved providers that it will cover those expenses even if the woman is determined ineligible after the formal Medicaid application process. Twelve States have adopted this coverage option, and we expect more will once they have developed State policy to approve providers.

The presumptive eligibility option should begin to address the problems of inadequate access to early prenatal care. Assuring that bills will be paid for initial visits reduces the woman's and the provider's uncertainty over payment and increases the likelihood that the woman will seek care and that the doctor will continue to provide care.

Some States have initiated other programs to simplify the Medicaid application process. Several State agencies have placed Medicaid eligibility workers at major hospitals, clinics, and large providers' offices to complete the Medicaid applications on site when the woman comes in for care. Seventeen States have dropped the assets test for pregnant women. Eliminating this test considerably speeds up processing of the Medicaid application because investigating the assets statement is a lengthy process.

Improvements in prenatal care have been accompanied by expanded Medicaid eligibility for children in poverty. Eleven States have opted to cover children through age 2 in families with incomes up to the poverty line.

An estimated 650,000 additional low-income women and children will be covered by Medicaid at the end of Fiscal Year 1989, and we will be spending approximately $255 million more in Federal dollars as a result of these coverage expansions.

In addition to expanded eligibility, many States have developed comprehensive prenatal care programs for high risk pregnant women. Among the innovative programs developed is one in South Carolina which channels these women through a special program providing a full range of prenatal and intra-partum care as well as ancillary services such as social work assessment, nutritional evaluations, and health education. This program is estimated to realize $3.1 million savings through reduced neonatal care and reduced institutionalization of children.

EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT (EPSDT)

Although recent Medicaid expansions have received a good deal of Congressional attention we should also give credit to the Early and Periodic Screening, Diagnosis and Treatment program.

This mandatory program, known as EPSDT, provides health screening and treatment to Medicaid recipients under age 21. The basic EPSDT screening and treatment services include: physical examination, developmental assessment, immunizations, nutritional assessment, vision and hearing tests, and some dental services.

The required services of this program are augmented with additional child health services by 24 States. For example through EPSDT, States can provide pre-pregnancy care and counseling to teenagers or target a specific package of prenatal services to pregnant teens. States may also offer broader services to EPSDT recipients than are otherwise offered under the Medicaid State plan.

Approximately 3 million Medicaid-eligible children received initial or periodic exams in Fiscal Year 1987. EPSDT provides an important access point into the health care system for many children. I am pleased to note that the American Academy of Pediatrics has assembled a resource handbook to encourage pediatrician support for the EPSDT program and to promote participation in the program.

Disabled Children

Another important responsibility of the Medicaid program is serving the nearly 300,000 children who meet the Supplemental Security Income (SSI) program's definition of disabled. Included in this group are children who suffer from AIDS; we estimate that 90 percent of these children receive Medicaid assistance.

Disabled children receive all of the basic Medicaid services but because of their special health care needs many receive additional support services in order to prevent institutionalization.

In 1981 and 1982, Congress passed legislation authorizing waivers and a State plan option, both of which permit States to pay for medical care administered to children in the home if home-care is less expensive than institutional care. These programs permits States to provide Medicaid to disabled children whose family income exceeds the SSI limits. There are 117 active waiver programs in 46 States, many of which serve children, and 13 States have adopted the State plan option.

Waiver programs have produced the most innovative approaches to providing for the special needs of the disabled and the complex needs of technology-dependent children. While there are many waiver programs worthy of note, I would like to describe two that have received the acclaim of parents and private insurers.

New Mexico Medically Fragile Children's Program

In New Mexico, children who are both chronically ill and developmentally disabled receive in-home care through the Medically Fragile Children's Program. This program, administered by the Coordinated Community In-Home Care Program within New Mexico's Department of Human Services and funded by Medicaid, offers a full range of medical and remedial services including case management, private duty nursing, homemaker/personal care and in-home respite, and home modifications. Thirty-seven children were served in 1987 and as many as 67 children may be served by 1990.

An independent evaluation of the program conducted by SysteMetrics found it to be highly successful because it is a consumer-driven program, emphasizes case management, and is cost-effective. The average cost per recipient in 1987 was $21,832 which represents about 66 percent of the average cost of serving such an individual in an intermediate care facility for the mentally retarded (ICF/MR). In addition to savings, the Systehetrics report revealed a high degree of parent satisfaction with the program.

Maryland Model Waiver for Ventilator-Dependent Children

Another waiver success story is the Maryland Model Waiver for Ventilator-Dependent Children. This Medicaid-funded program administered by the Coordinating Center for Home and Community Care, a nonprofit corporation, serves about 50 ventilator-dependent children in their homes and realizes a 50 percent cost savings. Since its inception in 1983 under a Maternal and Child Health special project grant, it has saved $3.2 million. Its success has led other third-party payers in Maryland, including the Blue Cross-Blue Shield Federal Employee Program, to hire the Coordinating Center for Home and Community Care to manage their technology-dependent beneficiaries. These private insurers have realized a 25 percent savings.

So in addition to saving tax dollars and improving care, some Medicaid waiver programs are so successful at saving money that they are being replicated by private health insurers.

END STAGE RENAL DISEASE (ESRD)

Another group of disabled children served through Federal dollars are those with end stage renal disease (ESRD) who qualify for Medicare coverage. To be eligible for Medicare ESRD benefits, a physician must certify that an individual requires dialysis or a kidney transplant in order to maintain life.

At the end of February of this year, nearly 2,000 children under age 19 were included in the Medicare ESRD dialysis population and 156 children received kidney transplants.

Medicare pays 80 percent of their outpatient services including outpatient dialysis, home dialysis equipment and supplies, physician payments, and self-dialysis training. Also covered are kidney transplant surgeries and costs associated with obtaining the donor kidney.

Departmental Studies on Improved Health Care

While we are proud of Medicaid's success at meeting the health care challenges of disabled children, we recognize that this is a continuing challenge. Therefore, the Department has established several working groups to explore policy and program directives to specialized populations.

We have a Low Birthweight Prevention group jointly chaired by the Directors of the Health Resources and Services Administration (HRSA), Maternal and Child Health Division, and the National Institute on Child Health and Human Development. HCFA participates in this group which is examining problems associated with pregnancies resulting in low birthweight babies and policies to improve our programs and decrease low birthweight outcomes in the future.

The Department's AIDS Taskforce is examining how to address the special needs of HIV-positive children. Of special concern are children abandoned in hospitals who require temporary or permanent living arrangements. We are examining how they can be assisted by Federal foster care and adoption assistance programs.

The Secretary also named a Working Group to examine a variety of cost-effective policy options to enhance the independence and productivity of developmentally disabled and mentally retarded persons and to increase opportunities for their integration into the community. The Working Group's draft proposals are being reviewed by various Department components.

Another area we are studying is services to technology-dependent children. The Task Force on Technology-Dependent Children was mandated to identify barriers that prevent home or community-based care for technology-dependent children and to recommend changes in providing and financing home-care. The Task Force is scheduled to report to the Secretary and Congress simultaneously. It is my understanding that the task force is preparing its final report and is expected to deliver it early next month.

Mr. Chairman, I am pleased to report that HCFA -- in partnership with State Medicaid agencies, Maternal and Child Health providers, and State public health officials -- is working effectively and innovatively to provide quality health care for millions of children in this country. The majority of States are expanding eligibility standards in order to cover more low-income women and children; expanding improved, cost-effective home care to many disabled children; and working to motivate providers to serve more Medicaid patients.

The aggressive, innovative approaches States are taking toward their responsibilities for children's health care demonstrates the kind of commitment we in the Medicaid program have to this critical sector of our society -- our children.

Thank you very much. I will be happy to answer any questions that you may have.

TESTIMONY OF JUDITH L. WAGNER

OFFICE OF TECHNOLOGY ASSESSMENT

U.S. CONGRESS

on

Issues in Health Care for Children

March 23, 1988

I am pleased to appear today to discuss children's health care issues. I am Judith Wagner, a Senior Associate in the Health Program of the Office of Technology Assessment (OTA) and project director of a recently completed OTA assessment of children's health.

OTA was requested by the House Committee on Energy and Commerce and its Subcommittee on Health and the Environment and by the Senate Committee on Labor and Human Resources to examine several important issues in children's health. OTA was asked to examine the effectiveness and costs of selected strategies for promoting and maintaining the health of children and to identify strategies whose implementation could substantially improve children's health or lower health care costs. The Committees also wanted to know why the infant mortality rate in the United States does not appear to be declining as fast as it has in the past and whether children have access to the health care they need. As you know, your Committee independently requested OTA to study a new medical technology called tocodynamometry that is used for monitoring pregnant women at high risk for preterm delivery.

Last month, OTA released its report entitled Healthy Children: Investing in the Future, which addresses all of the questions raised by the requesting Committees and presents options for Congress to consider in developing Federal policy. A separate Technical Memorandum published in May 1987, Technology-Dependent Children: Hospital vs. Home Care, examined the issues in financing and delivering appropriate health care services to children whose lives depend upon the continual application of sophisticated and costly medical devices and skilled nursing care.

My testimony draws from both of these OTA documents. I would like to focus on three issues addressed in the documents, but I would be happy to answer any questions you might have on the other issues we addressed. The three issues are:

-- the cost-effectiveness of expanding poor women's access to prenatal care;

-- young children's needs for improved access to primary care and well-child care;

-- problems in financing care for technology-dependent children.

The Cost-Effectiveness of Expanding Access to Prenatal Care for Poor Women

The high U.S. infant mortality rate in the United States is due in large measure to the high incidence of low birthweight births (defined as births under 5 lbs., 8 oz.). In 1980, low birthweight infants represented less than 7 percent of all live births reported in the United States but accounted for 60 percent of all infant deaths. Once birthweights are taken into account, U.S. infant mortality rates are comparable to, or even lower than, rates in other countries with much lower overall infant mortality rates.

OTA assessed the evidence on the effectiveness of early or enriched prenatal care on low birthweight and infant mortality. Despite serious shortcomings in the design of most studies of prenatal care effectiveness, the weight of the evidence from more than 55 studies indicates that low birthweight and infant mortality can be improved with earlier or more comprehensive care, especially in high-risk groups such as adolescents and poor women. Although the evidence clearly supports the effectiveness of prenatal care, the evidence is not strong enough to estimate with any confidence the size of the effect that can be expected from a given increase in the quantity or quality of prenatal care received by any segment of the population.

If prenatal care can improve birth outcomes, the logical next question is whether earlier or more frequent care is worth its costs. OTA estimated that for every low birthweight birth prevented, the U.S. health care system saves roughly between $14,000 and $30,000 in the cost of newborn hospitalizations, rehospitalizations in the first year of life, and long-term health care for illnesses and disabilities associated with low birthweight. OTA found that for every woman who receives earlier (i.e., first-trimester) prenatal care as a result of a program that encourages access, the extra costs of providing that earlier care would most likely be exceeded by the expected savings from the reduction in the rate of low birthweight. Of course, early prenatal care can also be expected to prevent some infant deaths (though the number cannot be predicted with certainty). Thus, increasing the use of early prenatal care is not only cost-effective, it is cost-saving to the U.S. health care system.

OTA examined the net impact on national health care costs (not just Medicaid costs) of one strategy to increase poor women's use of early prenatal care: adoption of universal eligibility for Medicaid of all pregnant women in poverty. OTA estimated that about 18 percent of the 196,000 newly eligible women (about 35,000 women) would shift from late or no prenatal care to first trimester care. The extra prenatal care services received by these women would be worth approximately $4 million nationally. We estimated that the receipt of earlier care by these 35,000 women would have to prevent between 133 and 286 low birthweight births for the societal health care savings to outweigh the prenatal care costs. If these women began with a low birthweight rate of 10.2 percent, that rate would have to decline by between 0.4 and 0.8 percentage points to a rate of between 9.4 and 9.8 percent for health care costs to break even.

Is it reasonable to expect reductions of this magnitude in the low birthweight rate among the women who take advantage of the expanded Medicaid benefits? The evidence on the impact of early prenatal care on birthweight suggests that such reductions are quite feasible. The quantitative results of several reasonably well-designed studies of the effect of early prenatal care on birthweight showed effects that were at least twice as great as those required for the expansion of Medicaid eligibility to pay for itself in reduced health care costs. In other words, encouraging poor women to obtain early prenatal care through expanded Medicaid benefits is a good investment for the Nation.

Our analysis did not conclude that this strategy would produce net savings to the Medicaid program itself, because Medicaid would pay for prenatal and maternity care that was formerly paid for by the poor women and their families, by other State programs, or indirectly by private patients through cross-subsidization for uncompensated care, but it would yield net savings to the health care system as a whole. Opportunities for both improving health status and reducing health care costs do not appear very often.

Simply expanding eligibility for Medicaid will not necessarily bring about large increases in early prenatal care unless other barriers to early care are also removed. In some States, the Medicaid enrollment process is complicated and lengthy and can delay the receipt of care for poor women. States could be encouraged or required to develop simplified eligibility requirements and procedures for pregnant women to enroll in Medicaid. Relatively inexpensive actions, such as developing simple applications for Medicaid benefits or placing Medicaid enrollment personnel in health clinics where many poor women first come for prenatal care, might encourage many women to sign up early in pregnancy for Medicaid.

Our study did not examine the implications for net health care costs of other strategies for increasing poor women's use of early or more comprehensive prenatal care. It is important to bear in mind, however, that the more intensive the services or the outreach efforts that are made to bring women into prenatal care early, the more costly the strategy will be. Each specific strategy would have to be considered in terms of its success as well as its costliness in increasing the use of early prenatal care.

Improved Access to Primary Care and Effective Well-Child Care for Young Children

OTA found a consistent relationship between family income and the use of ambulatory medical care by children--a relationship that appears to be stronger for sicker children. Data from the National Center for Health Statistics (NCHS) showed that in 1985, children from families with low incomes had fewer contacts with physicians than did children from families with high incomes. It appears that these differences are more pronounced in children suffering from health problems than in children in good or excellent health. In 1981, for example, NCHS reported that low-income children in fair or poor health made about 22 percent fewer visits to a physician than did middle- or high-income children with health problems.

Of course, the relationship between family income and children's use of health care services is mediated by the availability of health insurance, so that very poor children who have access to Medicaid are more similar to middle-income children in the frequency of use of medical care than are other poor or low-income children. However, poor children with Medicaid eligibility are more likely to obtain medical care at a hospital or public clinic than in a private physician's practice.

As might be expected, having a generous health insurance plan has a greater effect on the use of medical care for children in poverty than it does for other children. Poor children whose families pay a large amount out of their own pockets use much less care than do poor children who receive free care. Unfortunately, parents don't appear to be very good in differentiating between conditions for which medical care is highly effective and those for which it is not. When parents take their sick children to the doctor less frequently for financial reasons, they reduce effective and ineffective care in equal measure. Thus, the financial and other barriers to access faced by poor and near-poor children translate into less effective care for these children.

OTA estimated that in 1986, between 14 and 19 percent of all American children under 13 years of age had no health insurance eligibility whatsoever. About 61 percent of all children reported to be uninsured in 1986 were poor or near poor (family incomes between 100 and 150 percent of the poverty level). Almost 40 percent of poor children in intact families have no health insurance.

Despite the well-documented savings to the health care system of immunizations offered through well-child care visits (seven visits in the first 6 years of life are recommended for childhood immunizations), a substantial number of young children have not received their recommended immunizations. In 1985, over 20 percent of all 2-year-olds in the United States were not fully immunized against measles.

What can be done to improve the access of low-income children, particularly those who are without health insurance, to primary health care and appropriate well-child care? Congress could consider several options, some of which involve changes in the Medicaid program and others which involve expansion of direct services to children.

Congress has been expanding Medicaid eligibility for children since 1984. By July 1988, all children through age 6 who meet the income and resource requirements of the Aid to Families with Dependent Children (AFDC) program, regardless of whether they are actually eligible for AFDC, will be eligible for Medicaid. The AFDC income standards are State-specific, however, so the eligibility criteria are still varied and, in many States, stringent. In 1986, less than one-half of all American children under 13 years of age in poverty were covered by Medicaid. The Omnibus Budget Reconciliation Act of 1986 (OBRA-86) (P.L. 99-509) gave States the right to extend Medicaid on a phased-in basis to all children under 5 years of age whose incomes and resources put them below the Federal poverty line. As of January 1988, only 26 States had extended eligibility beyond the required levels. The recent optional expansions of eligibility under OBRA-87 (P.L. 100-203), which permit States to offer Medicaid to infants whose family incomes are below 185 percent of the Federal poverty level and to children up through age 8 with family incomes below the poverty line, will undoubtedly be implemented by only a minority of States.

By making Medicaid eligibility mandatory for all poor children through a certain age (such as age 5 or 8), Congress would reduce or eliminate the inevitable disparity among States that will result from the optional provisions of OBRA-87. While this option would improve the health of newly eligible Medicaid children by increasing their use of effective health care, it would also be likely to increase both Medicaid and health system costs, because it would bring about more use of medical care by these children.

An alternative to expanding Medicaid eligibility and increasing fee levels for Medicaid providers would be for Congress to increase direct Federal subsidies of health care providers that offer primary health care for low-income families. Real Federal funding of programs such as the Maternal and Child Health Services block grants, community health centers, and migrant health centers has seriously eroded over the past 10 years. Between 1978 and 1986, at the same time that the proportion of children in poverty rose dramatically. Federal appropriations for these three programs declined by 32 percent in constant 1978 dollars.

Increasing funding for direct provision of health services to poor children and pregnant women through the Title V program has the advantage of permitting States or localities to target services to areas of greatest need and to tailor programs to the needs of poor women and children. Programs of enriched prenatal care, for example, can be more easily coordinated through State or local governments or community health centers than through physicians' private practices.

By definition, however, the funding of public or publicly subsidized clinics for the poor tends to separate provision of care for poor children and pregnant women from care given to the nonpoor. The implications of separate streams of medical care for poor and nonpoor children are unclear. While targeted programs can offer enhanced services tailored to the multiple needs of poor children and their families, the quality and effectiveness of such services are likely to vary widely. Without freedom to use other settings of care, made possible by access to public or private health insurance, some poor women and children could receive lower quality care.

Problems in Financing and Delivering Health Services for Technology-Dependent Children

The last issue I would like to discuss is the challenge of serving some of our most medically vulnerable children--the up to 17,000 children who need both a medical device to compensate for the loss of a vital body function and substantial ongoing nursing care to avert death or further disability. These children are a small subset of the larger population of chronically ill children. They are characterized by particularly intensive medical care needs and high costs of care. They provide stark examples of the failure of the current health insurance system to provide flexibility for care outside of the hospital and of the poor coordination between private and public sources of payment for care.

Technology-dependent children are more likely than other children to lack adequate private insurance. When they are insured, their benefits often do not cover their extraordinary expenses, particularly in the home, and they are likely to use up their families' insurance benefits and other resources rapidly. High lifetime maximum benefits (e.g., $1 million rather than the still common $250,000) and individualized case-management programs that offer flexible benefits while a child is covered by private insurance can extend private coverage so long as the parent remains employed. Ultimately, however, virtually all very-long-term technology-dependent children who require a high level of nursing assistance will exceed the limits of their families' private insurance policies, will be uninsurable in the self-purchase insurance market, and will end up on Medicaid. Poor children, or those whose families are uninsured, must turn to Medicaid from the start.

In most States, Medicaid does not routinely pay for full-time home nursing and other complex home medical services. Nor are many technology-dependent children normally eligible for Medicaid until their families have become impoverished. Since 1981, however, the Federal Government has initiated three options available to the States for waiving their usual limitations. As of May 1987, however, less than one-half of the States had availed themselves of these options for enhancing the availability of Medicaid services to technology-dependent children outside of the hospital. One major roadblock to more extensive adoption of such waivers is the Federal requirement that the Medicaid agency must show that the home-based program will not cost the Medicaid program more money. Home services for children are not always cost-saving but depend on the care needs of the child and the home environment.

Federal support for technology-dependent children also comes through Title V State Services to Children with Special Health Care Needs programs (formerly called the Crippled Children's Services programs), which often both provide and coordinate services for them. The role of these agencies as a source of case management and coordination for children served under Medicaid waivers has been strong in some States. However, the freedom that allows State programs to choose which groups of children they will support also allows for extreme variation among States in available services and within States among disabled children who are eligible to receive extensive assistance. The result of these varied policies is that the availability of home medical care and related services for technology-dependent children depends greatly on the State in which the child lives and on the child's particular medical condition.

The key to solving the problems laid out above appears to lie in strengthening the ability of State and local agencies to coordinate services for these children. Help can come from the Federal Government in the form of increased Title V funds for direct services and case management, training for case-management personnel, and revisions of Medicaid that allow for individualized approaches to planning and paying for services for technology-dependent children. We need to keep in mind, however, that the larger the population of children covered under such flexible programs, the more daunting the prospect of individualized case management becomes.

That concludes my prepared remarks. I will be happy to answer any questions the Committee might have.

STATEMENT OF

GAIL R. WILENSKY

BEFORE THE SUBCOMMITTEE ON HEALTH

COMMITTEE ON FINANCE, U.S. SENATE

MARCH 23, 1988

Mr. Chairman, thank you for inviting me to testify before the Health Subcommittee. My name is Gail Wilensky. I am the Vice President of Health Affairs at Project HOPE. I am here, however, as an independent health policy analyst and not as a representative of Project HOPE.

The purpose of my presentation is to discuss health insurance coverage and health care spending by families of children with chronic diseases and high cost illnesses. In many ways, the problems of these families are similar to other families who are uninsured or underinsured, or who are impacted by a catastrophic illness or who have an adult, usually an elderly person, with chronic long-term care needs. There are, however, some important differences such as the number of years these families may have to face chronic care expenses, the burdens placed on multiple family members, special education needs for the children, and the particular problems these families face when the children reach young adulthood and may not be able to qualify for private insurance and may no longer qualify for public programs. It is also particularly important as we struggle to come to closure on acute care catastrophic coverage for the elderly, and intensify our discussion of their long-term care needs, to not forget this other "most vulnerable" segment of our society--the children.

Definitional Issues

Public discussion over what is meant by high cost illnesses usually involves a choice between defining the event in terms of disease entities or in terms of costs. Although a substantial amount of public pressure is sometimes generated by groups representing specific diseases, most people have recognized that disease specific categorizations can be misleading. Some cases within a particular disease may result in high costs while other cases may have low costs associated with them; similarly, some conditions that are normally not associated with high costs may on occasion result in very high costs. The financial burden of the disease is best reflected by its costs and not by the disease itself.

A second issue involves the distinction between single event high cost illnesses and chronic illnesses, which by their nature imply expenses being incurred over a substantial period of time. What is a noncatastrophic high cost illness if it occurs in a given year may become catastrophic if it occurs annually for five or ten years.

A third issue involves the distinction between high cost illnesses defined in absolute dollar terms and high cost illnesses defined relative to the family's income.

In general, I believe it is most useful to think about the problems of families with children with chronic illnesses in terms of the expenditures they incur, the period of time over which they incur them and the expenditures relative to the family's income.

Data Problems

As is true in many other areas of health care, relevant data are difficult, if not impossible, to obtain. There are at least two problems that make relevant data a particularly difficult issue in this area, in addition to the timeliness of data which is a problem in almost all areas of health care.

High cost illnesses and disabling conditions are rare events for children. This means that most national surveys that contain detailed information on health care utilization, expenditures and health insurance coverage will contain only a relatively few observations on children with high cost illnesses or with disabling conditions. Targeted studies, especially those focusing on specific diseases, are likely to contain a larger number of such cases but it is usually difficult to know how representative these estimates are, either of the nation as a whole or even those with a particular condition. In addition, most health surveys will contain relatively detailed information on hospital and physician expenditures, may contain some information on other health related expenditures but only rarely contain information on the social support expenditures associated with a chronic illness. The result is that the total cost of caring for children with chronic conditions is likely to be understated.

The implications of these data problems is that the information that is presented here, as well as the numbers available elsewhere, are usually a patchwork of estimates from national probability samples supplemented by costs taken from targeted studies, all of which are several years out of date. Despite these problems, there are numbers from different sources that seem to be consistent and trends that seem to make sense, given what else we know about what is happening in the health care system.

The Numbers

Numbers of Children:

The number of children who are reported to have some level of impairment varies somewhat according to the definition of disability being used. According to the Health Interview Survey, there were about three million children with a limitation in their activities in 1982, including almost one million who had some restrictions although not restrictions in their usual activity. About 200,000 were severely limited. A different survey, the Survey of Income and Program Participation, reported there were about two million children with a physical, mental or emotional disability as of 1985 that limited their ability to walk, run or play or their ability to learn.

Both surveys have indicated that disabled children are more likely to live in households with very low incomes, are more likely to live in households headed by women, and are more likely to be covered by Medicaid than nondisabled children.

Although we recognize that not all children with activity limitations have severe chronic illnesses and not all chronically ill children are restricted in their functioning, most of the utilization and expenditure data is available in terms of disabled children. Some of this information is summarized below.

Utilization and Expenditures:

Estimates from 1982 indicated that disabled children incurred costs ranging from an average of $870 to $10,229 per year for hospital and physicians services alone, depending on the severity of the condition. These expenses were between 3 and 38 times greater than the average incurred by children without disabilities. Medical care is significantly more intensive for disabled children than nondisabled children: nondisabled children average four physician visits per year compared to 9.5 visits for disabled children and 21.8 visits for children with severe limitations. Functionally limited, chronically ill children are four times more likely to be hospitalized than nondisabled children and once hospitalized, have an average length of stay twice that of children without disabilities.

The estimated total hospital and physician costs for moderately disabled children in 1982 were approximately $1600 per child, nearly six times the amount incurred for children without disabilities; hospital and physician costs for the most severely impaired children averaged over $10,000. These annual costs also do not reflect the disparity in accumulated lifetime costs of disabled children relative to nondisabled children.

Using data from the 1980 National Medical Care Utilization and Expenditure Survey adjusted for inflation, Paul Newacheck has estimated that the average annual expense in 1986 was $1,242 per disabled child, implying a total of $3.9 billion of expenditures for children with chronic impairments. As is the case for all medical expenditures, it is important to remember that a small number of children, even among the disabled, account for a disproportionately large share of the cost. About ten percent of the children accounted for 65% of total expenditures, a distribution very similar to that for total health expenditures.

A related area of concern involves the high costs of infants treated in neonatal intensive care units. About 150,000 to 200,000 infants are treated annually, about half of whom are low birthweight infants. The latter are among the most costly hospital admissions. On average, their hospital cost is $12,000 to $39,000, but the distribution is highly skewed. The tiniest infants (less than 750 grams) averaged $62,000 to $150,000. The success of neonatal intensive care is in part related to the increase in handicapped children. OTA has estimated that if today's neonatal care were provided for all very low birthweight infants, over 15,000 normal children who would have died in 1975 would be added to the U.S. population. In addition, about 2200 severely handicapped infants also would be added, who would not have survived in 1975.

Insurance Coverage:

Insurance coverage, because of its important role in determining access to health care, is particularly important for children with a disability. Information for both 1982 and 1985, indicates that children with a disability or limitation are slightly less likely to be uninsured than those without a limitation. Children with a limitation are less likely to be covered by private health insurance (66% versus 71%), but are substantially more likely to be covered by Medicaid. In addition, some children also benefit from other public programs such as Title V Maternal and Child Health Block grants or from private charities. These programs mostly serve the very low income. State crippled children agencies reported providing services to more than 620,000 handicapped children in 1984, almost all of whom were poor or low income.

Although children with impairments are less likely than other children to be uninsured, those impaired children who do lack coverage are particularly vulnerable. The decline in employer-based coverage for children that has occurred in the 1980s is particularly distressing as it relates to impaired children and is an issue that needs to be addressed for many reasons. Our concern, however, should not be limited to only those without insurance coverage. Some of the changes in insurance coverage which have occurred during the 1980s may also have adversely affected families of children with disabilities. During that time, many companies increased the levels of out-of-pocket expenses for premiums, deductibles and coinsurance. The effect of this, however, may have been partially offset by the increased use of "stop loss" provisions which limits the out-of-pocket liabilities that a family faces.

Other types of changes in insurance benefits may also have had mixed affects on families with disabled children. While many employers limited the scope of benefits provided by their insurance, these benefit changes frequently contained provisions for nonhospital care, such as the use of home health care and other types of care which may have assisted these families. In addition, case management which represents an important addition to families with disabled children, has been included with increased frequency.

Similarly, changes in Medicaid have had a mixed impact on families with disabled children, although on balance have probably been negative. Some states reduced the benefits being provided under Medicaid, adversely affecting families with disabled children. However, as a result of the Katie Beckett episode, federal regulations prohibiting Medicaid payment for home care were waived and served as the stimulus for model Medicaid waiver programs, allowing states to cover home and community-based care.

Policy Responses

The appropriate policy responses to assist families with chronically ill children are in general the ones appropriate for responding to the problems of the uninsured and the problems of catastrophic illness.

Employers who already provide insurance should be strongly encouraged to include catastrophic coverage--the cheapest form of insurance of all. Employers who do not now offer coverage should be strongly encouraged to do so--with incentives, administrative and informational assistance and, perhaps, if necessary, with some coercion. Medicaid also must do its share to cover the very poorest of children and a floor should be established, below which eligibility cannot fall. An additional policy strategy, important to the uninsured but especially important to this group, is the establishment of medically uninsurable pools. These pools can provide coverage to families whose members have pre-existing medical conditions, which will not otherwise be covered by most private insurance. The high risk pools will need to be subsidized since, by they their very nature, they involve high users and the subsidy will need to be financed by a broad-based tax which, because of the ERISA preemption, excludes insurance premiums as a potential base.

Finding a solution will require substantially more detailed information than we have currently available, about the number of disabled children, their illnesses, their use of health and other social services, the total costs of these services and the amounts currently being borne by the families and other payors. Even lacking this information, however, it is clear that ultimately the solution will require assistance from a number of different sectors--private and public; federal, state and local.

STATEMENT

BY

DR. ROBERT E. WINDOM
Assistant Secretary for Health
Department of Health and Human Services

HEARING ON CHILD HEALTH

MARCH 23, 1988

Mr. Chairman and Members of the Committee:
I welcome the opportunity to appear before you to discuss our common concern for the health of our Nation's children. I am joined by Dr. Vince Hutchins, Director of the Maternal and Child Health program.

There are many challenges that face us in public health but none is more important than assuring that our children are born healthy and able to grow and reach their full potential.

We commend you, Mr. Chairman, for focusing the efforts of your Committee this year on this crucial public health goal. As a parent and a physician, I am well aware of the consequences of health problems for children and their families. Our children's health status is a reflection of our own, and we have the responsibility to cure their ills and help them to achieve a healthy lifestyle. This is a philosophy I have encouraged at the Public Health Service (PHS).

INFANT MORTALITY

Seventy-five years ago, infant mortality was the first issue studied by the Children's Bureau. Since that time we have achieved substantial progress measured by a tenfold reduction in infant mortality. However, the continued unacceptably high rate of infant mortality, especially among Blacks, and our concern that the rate of decline has slowed in recent years keeps infant mortality as a major focus of this Department.

When Secretary Bowen joined the Department of Health and Human Services, he stated that of all the areas of concern he had, getting to the root causes of infant mortality was among his highest priorities.

As an expansion of our many efforts currently underway, Secretary Bowen has added another initiative to reduce infant mortality through the community and migrant health centers which serve some of our most vulnerable populations. This effort will provide enhanced services through a case-managed, comprehensive approach focused on the coordination of appropriate services throughout pregnancy and the first year of life.

PEDIATRIC AIDS

Let me also take a moment to mention the special Task Force on Pediatric AIDS which Secretary Bowen established last month. We are pleased that Dr. Bowen chose to lodge primary responsibility for the Task Force in the Public Health Service. The Chairman of the Task Force is Dr. Antonia Novello of the National Institute of Child Health and Human Development (NICHD).

Nothing is more tragic than the plight of infants affected with AIDS. The goal of the Task Force is to ensure coordination of all Department activities directed toward the care and treatment of these children, including research and demonstrations, and to determine the best use of our resources. A representative from the Health Care Financing Administration sits on the Task Force.

ELEVATION OF THE MATERNAL AND CHILD HEALTH PROGRAM

On Child Health Day, October 1, 1987, the PHS elevated the

Maternal and Child Health program from Division to Bureau level. This will enhance the visibility of the program, provide the opportunity to better coordinate child health activities, and establish a focus within the Federal Government for collaboration with other public agencies, professional organizations and voluntary associations.

Mr. Chairman, with your permission, I will provide an overview of child health activities at the Public Health Service beginning with the Maternal and Child Health program of the Health Resources and Services Administration.

MATERNAL AND CHILD HEALTH PROGRAM

As this Committee is well aware, the Maternal and Child Health (MCH) block grant program (Title V of the Social Security Act) provides formula-based allocations to States and insular areas for a broad range of health services including preventive, primary care, and habilitative services to mothers and children.

We intend for the States to have a great deal of flexibility in the use of these funds. Of the $526 million appropriated under Title V in Fiscal Year 1988, $444 million will go to the States in the block grant program.

Fifteen percent of the Title V funds are set-aside for grants administered by the national MCH staff for special projects of regional and national significance (SPRANS) in the areas of research, training, hemophilia, genetics, and special projects. We funded a total of 460 projects in Fiscal Year 1987 and we will spend $78 million this year to support approximately 490 projects. In a separate program, we have targeted approximately $3.8 million in Fiscal Year 1988 for newborn genetic screening, another important priority at the PHS.

Nationwide, a primary emphasis in MCH programs, which is responsible for a large measure of their success, is the integration of the Federal, State, local, and private efforts. Such collaboration encourages communication and keeps Federal priorities targeted in the needed areas and, moreover, it enables talents and resources to be used efficiently.

Infant health and prenatal care continue to be a top priority for the MCH program. We are seeking to expand our knowledge about factors which affect the health of mothers and infants, such as factors affecting low birthweight and physiologic triggers for normal and early labor so that we might learn to reduce the incidence of prematurity. We are working with States and communities to plan, deliver and evaluate the impact of health services for pregnant women and infants. And, we are reducing the barriers to care, particularly ethno-cultural barriers, so that we might bring high risk pregnant women into early prenatal care, and increase the access to care for minorities.

We are helping States and localities deal with special problems, such as medically fragile children and pediatric AIDS. To address pediatric AIDS, which represents a grave threat to the health of infants and children, we will soon be providing grants for demonstration projects to implement interventions to reduce the perinatal transmission of the HIV infection.

Chronically ill and disabled children require an array of services which can best be delivered in a community setting using case management to address medical, psychosocial and other needs. To the extent possible, these children deserve to live with their families in their own communities and to share in every day experiences most Americans take for granted.

The MCH program supports dozens of demonstration projects designed to implement family-centered, community-based delivery of services for disabled children of various age groups. Based on these examples, other communities will be able to replicate portions of these projects to serve their own children with special health care needs.

Additional major issues for the 1980s include:

Technology dependent children - We have pioneered the development of programs for these children and accelerated their movement from institutional settings to the home.

Hemophilia - We have demonstrated a cost effective model for the care of persons with hemophilia through support of regional hemophilia comprehensive care centers. We are assisting those centers and the population affected by hemophilia to cope with added complexities and safeguards which have resulted from the AIDS epidemic.

Genetics - We have initiated a major program in this new and rapidly expanding field. Our first emphasis was to support States in developing a capacity for genetic screening, counseling, and referral services.

NIH Child Health Research

In the area of research, virtually all of the Institutes and research components of the National Institutes of Health (NIH) are involved in funding or conducting child health research. In Fiscal Year 1987, the last year for which we have complete data, NIH expenditures for child health research totaled $600 million. The major focus for this research at the NIH is at NICHD.

A sampling of NIH child health research includes efforts to:

- Better understand and treat, and hopefully, cure and prevent, pediatric AIDS;

- Expand our ability to prevent prematurity and low birthweight, which are the leading causes of infant mortality;
- Prevent, treat or cure childhood diseases and disorders that range from cancer, heart disease, diabetes, and birth defects to Sudden Infant Death Syndrome;
- Develop new or improved vaccines to eradicate common infectious diseases that affect children such as Haemophilus influenza, and pertussis;
- Prevent and ameliorate the impact of mental retardation;
- Find ways to prevent childhood injuries, which kill more U.S. children each year than all childhood diseases combined; and
- Improve our efforts to diagnose and treat learning disabilities.

IHS Child Health Activities

The health of American Indian and Alaska Native (AI/AN) children receives priority attention by the Indian Health Service (IHS). The IHS recognizes that the well being of the AI/AN community is measured by the health of its children and that the future health of the AI/AN community is secure when children of today are healthy. Although there is no specific allocation for child health in the IHS budget, we estimate that approximately $225 million is directed toward child health activities.

In the IHS, we provide maternal and child health (MCH) services through a regionalized health care system. For basic preventive and direct health care services, we have trained indigenous health workers and professionals in the field and service unit facilities. Thereafter, we have referral, consultative and transfer linkages with secondary and tertiary facilities. Within this regionalized system, culturally acceptable and readily accessible preventive health care is emphasized.

In close collaboration with the American College of Obstetricians and Gynecologists, we provide postgraduate training in prenatal and perinatal health care for our IHS primary health care providers. At IHS headquarters, we establish MCH policies and standards of care which we review periodically. Since its inception, the IHS has made remarkable progress in infant mortality reduction.

CDC Child Health Activities

Our Centers for Disease Control (CDC) has a long history of assisting States and communities in improving infant and child health. CDC expenditures for child health exceed $100 million.

Ongoing CDC activities include infectious disease control through childhood immunization, and the reduction of birth defects through national surveillance and targeted epidemiologic studies to identify factors responsible for these conditions. Our efforts in the area of infection control now include surveillance and epidemiologic studies related to day care center outbreaks and Reye Syndrome, as well as expansion of efforts to prevent transmission of hepatitis B virus (HBV) from HBV carrier mothers to their infants. We have also developed guidelines on the control of infectious diseases in day care settings.

More recently, we have increased our efforts in CDC to address low birthweight, the primary contributor to infant mortality. Many of our newer activities focus on the prenatal period. We are assisting State health departments to expand the surveillance of a wide variety of risk factors in pregnancy associated with low birthweight, including smoking, poor nutrition, and excessive alcohol consumption. Data gathered from these surveillance efforts enable the States to improve the targeting and effectiveness of prenatal and infant health care. We also have efforts underway to develop effective smoking cessation interventions among high-risk women in order to prevent the one-fourth of low birth weight that is related to maternal smoking.

I would also like to mention that CDC has contributed to child health by launching a comprehensive injury prevention research initiative including projects that identify causes, consequences and methods to prevent injuries among children; improve childhood injury prevention counseling by physicians; and identify ways to increase the use of safety belt/child restraints in automobiles. Finally, we have been a leader in the fight against lead poisoning in children by providing laboratory services, outreach, resource development, environmental epidemiology, and lead hazard services.

ADAMHA Child Health Activities

The Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) administers a variety of program activities related to child health. ADAMHA expenditures for child health approximate $30 million.

In the National Institute on Mental Health, we are undertaking research on all aspects of child and adolescent disorders, including autism, attention deficit disorders, conduct disorders, affective disorders, anxiety disorders, eating disorders, learning disorders, mental disorders associated with mental retardation and somatic illness, and Tourette's syndrome. Also, a high priority has been placed on youth suicide research.

In addition, the Institute administers the Child and Adolescent Service System Program, a service demonstration program designed to improve States' capacities to meet the needs of severely emotionally disturbed children and adolescents. Grants are made at State and local levels and emphasize such activities as: 1) interagency coordination; 2) identifying and prioritizing the population within the State mental health system; 3) increasing family participation in treatment planning; and 4) increasing the appropriateness of service delivery to the special needs of cultural/ethnic minorities.

Our National Institute on Drug Abuse (NIDA) conducts and supports research on drug abuse as it affects children and adolescents directly and through maternal drug use during pregnancy. Prevention, prenatal care, diagnostic measures, and developmental interventions are addressed.

A major epidemiologic study is the NIDA-supported annual survey of high school seniors that provides data about the drug use behavior of the Nation's youth. Adolescent issues are addressed further through research such as a study at NIDA's intramural Addiction Research Center on noninstitutionalized delinquent adolescents who are at higher risk for drug abuse because of their aggressive behaviors.

NIDA's AIDS research includes a focus on preventing perinatal infection that is related to a parent's intravenous drug abuse. In addition, we support investigation into the early developmental and neurologic consequences of HIV infection in children.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) places a high priority on studies to understand the mechanisms of prenatal alcohol damage, particularly because such knowledge could lead to specific therapeutic interventions to prevent or repair such damage.

Our intramural researchers are currently studying cognitive function in the children of alcoholics based on the premise that differences in abstract thinking and problem solving abilities in these children may contribute to their use of alcohol as they mature.

The Office of Substance Abuse Prevention (OSAP) within ADAMHA administers the high-risk youth demonstration grants program established by the Anti-Drug Abuse Act of 1986. While targeted at child substance abuse problems, these 130 grants also overlap into other areas of child health.

Mr. Chairman, I have highlighted a few of our many vital child health activities. You can see that the child health challenges of today require the skills and energy of all segments of our society. Issues such as injuries, risk taking behaviors, and interpersonal violence require the involvement and attention of not only the medical care system but also parents and schools. Mr. Chairman, this concludes my prepared statement. Additional Public Health Service child health activities are described in greater detail in an attachment to my statement. I will be happy to answer any questions you may have.

A FULL SUMMARY OF IHS'S CHILD HEALTH ACTIVITIES

The health of American Indian and Alaska Native (AI/AN) children receives priority attention by the Indian Health Service (IHS). The IHS recognizes that the well being of the AI/AN community is measured by the health of its children and the future health of the AI/AN community is secure when children today are healthy.

Data are available which focus the direction of the program efforts and the resource needs to AI/AN children. Of the total AI/AN population, 45% are under 20 years of age and 32% are less than 15 years of age according to the 1980 Census. 25% of the total population are women of child-bearing age (15-44 years of age). AI/AN women currently have a Total Fertility Rate of 3018 live births per 1,000 women 10 to 49 years of age. This contrasts with the general U.S.A. (all races) rate of 1806. Therefore, not only are large portions of IHS effort and resources directed toward the needs of children now, but will be required well into the 21st century.

The IHS provides maternal and child health (MCH) services through a regionalized health care system. Basic preventive and direct health care services are first provided by trained indigenous health workers and professionals in the field and service unit facilities. Referral, consultative and transfer linkages with secondary and tertiary facilities are then made. Within this regionalized system of health care, culturally acceptable and readily accessible preventive health care are emphasized.

In close collaboration with the American College of Obstetricians and Gynecologists, the IHS provides postgraduate training in prenatal and perinatal health care for its primary health care providers. At the IHS headquarters, MCH policies and standards of MCH care are established, and the implementation of these standards by Area MCH consultants is periodically reviewed. Thus, regionalized health care, including local access, efficient consultation, referrals, and consistent standards and policies form the basis of the successful IHS program.

There are specific areas of attention and activities relating to children's health which should be noted.

1. Infant Mortality.

The overall AI/AN infant mortality rate for 1983 to 1985 is 9.8 infant deaths per 1000 live births, a rate that is less than the rate of the U.S. All Races. When this infant mortality is examined more closely, it is found that neonatal (birth to 27 days) mortality is considerably lower than the rate of U.S. All Races, but the postneonatal (28 days - 1 yr) mortality for AI/AN infants is 1.3 times that for the U.S. All Races. The IHS is focusing on the postneonatal infant mortality in several ways.

a. Each IHS Area receives a yearly $20,000 allocation to reduce the incidence of Fetal Alcohol Syndrome.

b. The IHS is collaboratively involved in studies of Hemophilus influenza type b (Hib) vaccine efficacy. The effectiveness of Hib conjugate vaccines are being evaluated in Alaska Native and Navajo infants. Additional studies with immune globulin (Bacterial Polysacchoride Immune Globulin) are occurring at San Carlos and Whiteriver, Arizona. These studies should lead to the elimination or control of the most important bacterial infection in AI/AN infants.

c. In collaboration with the Centers for Disease Control (CDC) and the State of Alaska, the IHS successfully carried out a Hepatitis B prevention program in Alaska. A priority target in that program is the identification of and protection of infants at risk of Hepatitis B.

d. The IHS has a vigorous infant and childhood immunization program. The overall immunization level for AI/AN children 3 to 27 months of age is 89.7% for Dipheria/Tetenas/Pertussis and 94.9% for Oral Polio Vaccine. Program emphasis, careful monitoring by an IHS immunization director and field efforts by community health nurses have led to these excellent levels, which exceed that of the general population.

e. The IHS, in collaboration with the American Academy of Pediatrics (AAP), is intensively studying postneonatal infant mortality in the Portland, Aberdeen, and Billings Areas. Additional studies are also occurring in collaboration with CDC in Alaska. Risk factors in postneonatal infant mortality will be determined and will be useful in establishing programs of intervention.

f. The IHS is placing emphasis on reaching the PHS 1990 "Objectives for the Nation", especially addressing the need for comprehensive well child care.

g. The IHS contracts with the American Academy of Pediatrics Advisory Subcommittee on Indian Health to periodically review IHS infant and child care services and to advise the Director of IHS on program weaknesses and strengths. It is important to note that even though the postneonatal mortality rate of American Indians exceeds that of the U.S. general population, it has fallen from 20.7 per 1000 live births in 1965 (when it was 3 times greater than the U.S. All Races) to 5.3 per 1000 live births (a decrease of nearly 300 percent). This dramatic fall is evidence of the success of the IHS programs.

2. Healthy Pregnancy.

The IHS recognizes that early and consistent prenatal care is vital to the health of infants and the IHS MCH Coordinator gives priority attention to access to prenatal care. Personnel in several service units have identified population subsets who give birth to the most at-risk newborns and thus are able to more effectively focus program resources.

Additional activities which contribute to the community oriented public health approach embraced so successfully by the IHS include:

a. Maintenance of a High Risk Obstetric/Neonatal program in each IHS Areas to provide tertiary care for those in high risk categories and for programs designed to prevent high risk pregnancies or births;

b. Under the direction of the IHS Senior Clinician in Obstetrics and Gynecology, IHS [illegible] upgrades obstetrical services in IHS facilities. At least [illegible] of all IHS births are attended by a trained health care professional and 82% of the births are under the direct supervision of an IHS obstetrician. More obstetricians and certified nurse midwives are being recruited in order to provide full service obstetrical care;

c. Under the direction of the IHS Diabetes Program Director, IHS is establishing standards for the identification of and management of gestational diabetes. Area diabetes coordinators are implementing these standards and providing educational programs for IHS professionals; and

d. The IHS has a contract with the American College of Obstetricians and Gynecologists Committee (ACOG) on Indian Health to review and make recommendations about maternal health care provided by the IHS.

3. Handicapped Children.

The IHS is giving increased program attention to the needs of AI/AN children with handicapping conditions and chronic diseases. The number of AI/AN children requiring interdisciplinary and interagency special services is estimated to be as many as 50,000. The following activities are being directed toward meeting the special needs of handicapped AI/AN children:

a. The IHS is developing an interagency agreement with the BIA Office of Indian Education Programs as a step toward coordination of IHS services with those responsibilities of the BIA and state agencies under the Education for all Handicapped Children's Act.

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b. The IHS is developing a computerized program for registration and tracking of children with handicaps and with chronic diseases. This program will be implemented throughout the IHS.

c. A position has been established in Headquarters to head up a national technical assistance team and to coordinate handicapped children's programs in the IHS. This position will be responsible for implementing the BIA-IHS interagency agreement, establishing standards and policies, and assisting all IHS Areas in enhancing their capabilities to serve the needs of handicapped AI/AN children. This program will assist BIA and state education agencies to meet the requirements of the Education for all Handicapped Children Act of 1975, P.L. 94-142, as amended by P.L. 99-457.

4. Child Abuse and Neglect (CA/N).

Child abuse and neglect is a growing problem and concern for the IHS. Skillful, sensitive, and effective services are needed to confront the complex personal, family, and community needs where CA/N occurs. In order to deal with this situation the IHS has undertaken a series of steps.

a. Child Protection Teams (CPT) are being established in every IHS Area and Service Unit.

b. Through an interagency agreement with the BIA Social Services, these CPTs have been expanded to ensure cooperation with the BIA and with tribal agencies.

c. Baseline data are being collected in order to establish the extent of the CA/N and to monitor program effectiveness.

5. Adolescent Health.

Health care for AI/AN youth are as specialized as for the rest of the population. Established health care methods are often inaccessible or unacceptable to AI/AN adolescents. Teen pregnancy is of particular concern to the IHS. During 1983-1985, twenty percent of AI/AN babies were born by women under 20 years of age. During 1983-1985, AI/AN youth aged 15 to 24 years experienced a suicide rate 2.1 times that for the U.S. All Races youth. Much, and perhaps most, of this destructive behavior is believed to be alcohol related.

a. The IHS, through an interagency agreement with the Bureau of Health Care Delivery and Assistance, is providing $300,000 to establish an adolescent health data base. Over 40,000 AI/AN adolescents served by the IHS will complete the Minnesota Adolescent Health Attitudes questionnaire. These data will provide invaluable information with which relevant adolescent health programs can be planned.

b. Many IHS Areas are involved in school based Teen Clinics. The objective of these clinics is to provide accessible and acceptable health services and to provide education leading to reduced teen pregnancies.

c. With funds made available through the Indian Alcohol and Substance Abuse Prevention and Treatment Act of 1986, P.L. 99-570, the IHS has distributed $9,000,000 to the IHS Areas to develop and staff community-based rehabilitation and after care services for youth with drug and alcohol abuse problems in every Service Unit whether managed by IHS or by a tribe under the Indian Self-Determination Act, P.L. 93-638. Two centers for treatment of youth are ready to open -one in Tahlequah, OK, and another in Acoma-Canoncito-Laguna, NM. Additional contract funding is being provided for inpatient treatment of youth residing in other IHS Areas. Funds to train tribal leadership and BIA and IHS personnel in treatment and management of patients with alcohol and drug abuse problems are also available.

E. Oral Health.

Surveys have consistently demonstrated that American Indian and Alaskan

Native children have a greater prevalence of oral disease and higher treatment needs than other U.S. children of comparable age.

The caries prevalence study conducted by the National Institute of Dental Research (NIDR) in 1979-80 indicated that nearly 40% of U.S. children aged 5-17 years were now caries-free. This compares to an IHS survey in 1983-4 which found that less than 20% of comparably aged AI/AN children had not experienced tooth decay.

This same survey revealed that over half of Indian children under age 5 have suffered from baby bottle tooth decay (BBTD), a rapid destruction of the primary dentition resulting in pain, infection, and loss of oral function as well as potential adverse effects on the permanent teeth.

A recent survey by the NIDR at the Ft. Wingate Indian High School demonstrated a prevalence of early periodontal disease - loss of the supporting structures of the teeth - that is higher than any other comparable age group studied in the U.S. to date.

Preliminary studies of smokeless tobacco use indicate that Indian children are frequent users of this substance, which has been linked with tooth decay, destruction of the supporting structure of the teeth, and oral cancer. This is of special concern in a population known to be predisposed to diabetes.

Several initiatives have been undertaken to control the development of new disease:

a. An interagency agreement with the Administration for Children, Youth & Families (ACYF) supports an intensive health promotion effort to raise community awareness of BBTD as a major health problem in young children.

b. The water fluoridation program has been steadily expanded since 1980 with 80% of water systems with fluoridation equipment providing adequate levels of fluoride to AI/AN communities. This is compared to only 30% in 1962.

c. In areas where water fluoridation is impractical or only recently initiated, programs of supplemental fluorides are prescribed for children.

d. The utilization of dental sealants to prevent decay from developing in the pits and grooves of the teeth has increased phenomenally since 1986. Provision of these services is focused on children ages 6-8 and 11-13 years in order to allow sealing of the permanent molars as soon as possible after eruption.

e. In collaboration with the CDC, a task force has been established to identify strategies to control periodontal disease. Using a methodology developed by the World Health Organization, the periodontal status of adolescents is being assessed throughout the IHS. This will provide baseline data to measure the effectiveness of future efforts, as well as provide information for better targeting of these efforts.

f. Increased resources are being dedicated to disease prevention/health promotion. With the support of the Centers for Disease Control (CDC), educational efforts to discourage use of smokeless tobacco have been initiated.

g. Demand for orthodontic services for Indian children is increasing. Although only a very limited amount of resources can be devoted to this treatment service, the IHS, in conjunction with researchers from the University of Iowa, is exploring the development of a rational priority system to ensure that orthodontic services are allocated to those children in greatest need.

h. Providing access to basic dental services to all family members is encouraged in an attempt to reinforce the child's concept of the importance of oral health.

7. Injury Control.

During Calendar Years (CY) 1981-85, 426 AI/AN children under the age of 5 years died as a result of injury. Their death rate was 87 deaths per 100,000 (or 4.5 times the U.S. All Races rate of 15.4 deaths per 100,000 population). Motor vehicles, falls, drowning, and fires are the leading causes of death from accidents.

The importance of injuries to the health of American Indians is well illustrated by the Years of Productive Life Loss (YPLL) before age 65. An analysis of all causes of YPLL for 1981-1985 reveals that 45 percent of YPLL was attributable to injuries. To put this in perspective it should be noted that heart disease and diseases of the digestive system were the second and third leading causes of YPLL, each accounting for 7 percent each of the nearly 576,000 years of life lost prematurely.

Recognizing the importance that injuries play in the early years of one's life, the Indian Health Service has targeted a number of projects to prevent or minimize the pain and suffering from accidents. As we all know, the best prescription for good health is PREVENTION. I would like to share with you some information about the projects initiated by the IHS to prevent injuries. Most of these projects afford protection to children, teens, and adults alike. Other are targeted to children alone.

a. "Buckle Up Your Unborn Baby" is a project initiated in the Phoenix Area to reduce maternal/fetal deaths. Motor vehicle crashes were the leading cause of maternal/fetal deaths, exceeding hemorrage and toxemia. This project is conducted through the OB/Gyn clinics where pregnant women are encouraged to wear their safety belts and to buckle up their newborns in approved child safety seats.

b. "Child Passenger Protection" programs now exist throughout Indian Country. IHS is pursuing a policy which would require Indian infants to receive safety seats as part of the newborn layette.

c. The "Indian Safety Campaign" was developed to call attention to the devasting toll that injuries take on the lives of Indian and Alaska Native people each year. A key element of this campaign is a poster competition conducted in schools on or near Indian reservations throughout Indian country. During the 1987-8 contest, approximately 30,000 Indian youth submitted posters with a safety theme. Eight national winners were selected and will come to Washington D.C. for an awards ceremony with Secretary Bowen.

d. "Roadway/Roadside Hazard Identification" is an area of great attention in the IHS due to the overwheling influence that motor vehicle crashes have on the deaths and hospitalization of Indian people. This project identifies specific crash locations by pin mapping with follow-up on-site investigations with highway officials to determine critical environmental factors contributing to the crashes. Significant progress has been made with the help of the Federal highway Administration to identify and correct road conditions on Indian reservations.

e. "Injury Surveillance" or case histories are the real key to identifying the significant contribution factors to injury occurrence and ultimately determining what corrective action should be taken. All IHS Areas have initiated the use of injury surveillance on the most severe injury cases. This provides an epidemiologic analytic approach which will serve as the basis for targetted programs.

f. The "National American Indian Housing Council" has requested assistance from the IHS in developing a safety and risk management program for Indian Housing Authorities throughout the country. This project will highlight the need for improved home conditions to minimize hazardous situations. Emphasis will be placed on smoke detectors, water heater temperatures, poison prevention, wood burning stoves, and grease fires.

g. The "Injury Control Specialist Fellowship" is a unique training program offered to IHS and Tribal Health Professionals to better understand the epidemiology of injuries and to develop skills in designing, implementing, and evaluating community-based intervention projects. The fellowship was begun in FY 1987 with 11 fellows and expanded to twenty fellows in the FY 88 class.

Although the IHS Injury Control Program is in its early infancy, evidence of declining injury rates are encouraging.

E. Sanitation.

An important aspect of the Indian Health Service progress in improving the health of AI/AN children has been the implementation of a comprehensive environmental health program which includes the provision of safe water supplies and the construction of sanitary waste disposal systems. A review of the infant mortality rates indicates that during the 1966 to 1984 time period the AI&AN post-neonatal mortality rates centered in these years dropped from 20.7 infant deaths per 1,000 live births to 5.3 infant death per 1,000 live births. During the same period the U.S. All Races rate was reduced from 6.5 to 3.8 infant deaths per 1,000 live births.

We believe a significant portion of this reduction can be traced to the provision of safe water and sanitary waste disposal and that our continuing efforts in this area will greatly assist in continued inprovement in the AI/AN mortality rate. The 1985 annual adjusted mortality rate due to gastrointestual diseases for all ages for AI/AN was lower than the U.S. All Races rate.

In summary, the PHS provides a wide range of traditional and innovative approaches to improving the health of AI/AN youth. The results of this public health service model of health care has been astounding and is reflected in the rapidly declining death rates of this group of Americans.

A FULL SUMMARY OF CDC'S CHILD HEALTH ACTIVITIES

The Centers for Disease Control (CDC) has a long history of assisting States and communities in improving infant and child health. Activities that have been ongoing for some time include infectious disease control through childhood immunization and the reduction of birth defects through national surveillance and targeted epidemiologic studies to identify factors responsible for these conditions. Efforts in the area of infection control now include surveillance and epidemiologic studies related to day care center outbreaks, Reye's syndrome, and rotaviruses as well as expansion of efforts to prevent transmission of hepatitis B virus (HBV) from HBV carrier mothers to their infants. CDC has also developed guidelines on the control of infectious diseases in day care settings.

More recently, CDC has stepped up its efforts to address low birth weight, the primary contributor to infant mortality. Since the potential for prevention of low birth weight occurs before or during pregnancy, many of CDC's newer activities focus on the prenatal period. A recent Departmental initiative is assisting State health departments to expand the surveillance of a wide variety of risk factors in pregnancy associated with low birth weight including smoking, poor nutrition, and excessive alcohol consumption. Data gathered from these surveillance efforts enables State health departments to improve the targeting and effectiveness of prenatal and infant health care. An initiative is also underway to develop effective smoking cessation interventions among high-risk women in order to prevent the one-fourth of low birth weight that is related to maternal smoking.

Other CDC activities relating to the health of children include:

- surveillance of the nutritional status of high-risk children that provides information on the prevalence of overweight, underweight, and retarded linear growth, and on cases of severe pediatric undernutrition.

- the provision of quality control services to laboratories that screen all newborn infants for conditions that can cause mental retardation if not detected and treated soon after birth. CDC and the Georgia Department of Human Resources are conducting the only United States population-based surveillance for five developmental disabilities: mental retardation, cerebral palsy, blindness, deafness, and epilepsy.

- providing technical assistance in combatting lead poisoning in children through outreach, resource development, environmental epidemiology, lead hazard reduction and laboratory services to the Health Resources Services Administration as well as to States and communities.

CDC has expanded its injury control activities by launching a comprehensive injury prevention research initiative with a major focus on infants and children. Components of this initiative include:

  - identifying causes, consequences, and ways to prevent brain injuries among children;
  - evaluating and improving the effectiveness of childhood injury prevention counseling provided by physicians to parents;
  - and determining the most effective ways to increase safety belt/child restraint use among infants and children.

Together, these CDC efforts provide essential information and technical assistance that support infant and child health program planning and evaluation at the Federal, State and local levels.

A FULL SUMMARY OF ADAMHA'S CHILD HEALTH ACTIVITIES

The National Institute on Mental Health (NIMH) is undertaking research on all aspects of child and adolescent disorders, including autism, attention deficit disorder, conduct disorder, affective disorders, anxiety disorders, eating disorders, learning disorders, mental disorders associated with mental retardation and with somatic illness, and Tourette's syndrome. A high priority has been placed on youth suicide research. In addition, the Institute administers the Child and Adolescent Service System Program, a service demonstration program designed to improve States' capacities to meet the needs of severely emotionally disturbed children and adolescents. Grants are made at State and local levels and emphasize such activities as: 1) interagency coordination; 2) identifying and prioritizing the population within the State mental health system; 3) increasing family participation in treatment planning; and 4) increasing the appropriateness of service delivery to the special needs of cultural/ethnic minorities.

The National Institute on Drug Abuse (NIDA) conducts and supports research on drug abuse as it affects children and adolescents directly and through maternal drug use during pregnancy. Prevention, prenatal care, diagnostic measures, and developmental interventions are addressed.

A major epidemiologic study is the NIDA-supported annual survey of High School seniors that provides data about the drug use behavior of the Nation's youth. Adolescent issues are addressed further through research such as a study at NIDA's intramural Addiction Research Center on noninstitutionalized delinquent adolescents who are at higher risk for drug abuse because of their aggressive behaviors.

NIDA's AIDS research includes a focus on preventing perinatal infection that is related to a parent's intravenous drug abuse. In addition, NIDA supports investigation into the early developmental and neurologic consequences of HIV infection in children.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) places a high priority on studies to understand the mechanisms of prenatal alcohol damage, particularly because such knowledge could lead to specific therapeutic interventions to prevent or repair such damage. NIAAA awarded in 1987 a grant to Wayne State University to establish a new National Alcohol Research Center to systematically study alcohol-related birth defects and continues to fund many individual research projects on all aspects of prenatal alcohol exposure.

NIAAA intramural researchers are currently studying cognitive function in the children of alcoholics based on the premise that differences in abstract thinking and problem solving abilities in these children may contribute to their use of alcohol as they mature. NIAAA researchers have demonstrated that adolescent children of alcoholics are more likely to be impulsive and less likely to be reflective than similarly-aged children of non-alcoholics.

The Office for Substance Abuse Prevention (OSAP) within ADAMHA, administers the high risk youth demonstrations grants program established by the Anti-Drug Abuse Act of 1986. While targetted at child substance abuse problems, the 130 grants also overlap into other areas of child health such as child neglect or abuse, teen parenting, children of substance abusers, homeless and runaway children, latchkey children, mental illness and suicide in children, physical disabilities, and the economically disadvantaged.

Finally, the Alcohol and Drug Abuse and Mental Health Services Block Grant (Part B, Title XIX, PHS Act) provides Federal funding to all the States to assist them in providing alcohol, drug abuse, and mental health services. There are no age restrictions on the populations a State may wish to target to receive treatment and prevention services. While the amounts vary from State to State, it is safe to say that a significant portion of this funding ($643,235,000 in FY 1988) is targeted for treatment and prevention services for adolescents.

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May 25, 1988

Dr. Robert E. Windom
Director
Public Health Service
200 Independence Avenue, S.W.
Room 716G
Washington, D.C 20201

Dear Dr. Windom:

As a follow-up to the question about childhood immunization that I asked you at the March 23, 1988 Finance Committee Hearing on children's health care, I would like to ask the following question:

Though the childhood immunization program in the U.S. is considered an overall success, a close look at the program does reveal some troubling trends. Most notably, continued increases in vaccine prices have caused shortfalls in federal and state immunization funding. Further, there has been a stagnation and decline in immunization levels for preschool children.

In light of these trends, why did the Centers for Disease Control, in its FY 89 budget, request a level of funding for the vaccine program that would provide enough money to purchase the same amount of vaccine as last year, but only at the expense of eliminating the programs to administer the shots and stockpile emergency vaccines?

Thank you for your time and consideration, and I look forward to your reply.

With best wishes, I am

Sincerely,

Tom

Tom Daschle
United States Senate

TAD/rjc
cc: Mr. Edward McGroarty
Office of Health Legislation

194518

DEPARTMENT OF HEALTH & HUMAN SERVICES
Public Health Service

Office of the Assistant Secretary
for Health
Washington DC 20201

JUN 21 1988

The Honorable Tom Daschle
United States Senate
Washington, D.C. 20510

Dear Senator Daschle:

Thank you for your letter of May 25 in follow up to the March 23, 1988 Finance Committee Hearing on children's health care. You asked "...why did the Centers for Disease Control, in its Fiscal Year 1989 budget, request a level of funding for the vaccine program that would provide enough money to purchase the same amount of vaccine as last year, but only at the expense of eliminating the programs to administer the shots and stockpile emergency vaccines?"

Over the last five years, the cost of vaccines has increased tremendously. Consequently, we have had to make fiscal choices about how the funds allocated to us would be spent best. We realize that "State Operations" is a very important component of immunization programs; however, the provision of vaccines remains our highest priority and vaccines must be purchased before they can be delivered.

In an effort to help insure that States and localities would have an adequate vaccine supply, and to help offset the costs of "State Operations," grant guidelines have been revised to permit local clinics to request an administrative fee or donation when vaccines are administered. However, it is important to note that no child may be denied an immunization because of inability to pay a fee.

In regards to funding for the vaccine stockpile, we expect to have an average 19-week supply accumulated by the end of Fiscal Year 1988. Further buildup of the stockpile was viewed as a lesser need than, for example, insuring sufficient resources to assist the States in purchasing vaccines for the immunization program. We do not anticipate a major interruption in the supply of vaccine; therefore, delaying the completion of the stockpile by one year should not have an impact on the childhood immunization program.

Sincerely yours,

Robert E. Windom, M.D
Assistant Secretary for Health

COMMUNICATIONS

CRS REPORT FOR CONGRESS

HEALTH CARE FOR CHILDREN: FEDERAL PROGRAMS AND POLICIES

March 17, 1988

ABSTRACT

This report provides background information on health care for children, including information on primary health care for children and health care for children with chronic conditions. It includes appendixes which supply an overview of three health programs under the jurisdiction of the Senate Committee on Finance: Medicaid, the Maternal and Child Health Services Block Grant, and Medicare's End-Stage Renal Disease program. In addition, a final appendix summarizes Federal Government policies, including tax policies, which may affect health insurance coverage of children. This report was prepared at the request of the Senate Committee on Finance.

HEALTH CARE FOR CHILDREN

SUMMARY

Primary care for children is provided at the point where the child enters the health care system and receives basic ambulatory services. Some health analysts maintain that patterns of childhood illness indicate the need for children's health services to focus on primary care. Primary care for children is aimed not only at treatment, but also at prevention. Children's access to primary care services varies by age, family income level, race and ethnicity, and by health insurance status.

Most children in the United States are covered by health insurance. Sources of health coverage include private health insurance plans and government programs. Poor and near-poor children are less likely to be covered. Concern about uninsured children exists because they have lower levels of medical care use and may expose their families to larger proportions of out-of-pocket expenditures and the risk of extremely high health care costs. Health insurance plans may have limited benefit limits and other features which can expose families to out-of-pocket expenses.

Medicaid covers about one-half of all poor children. Medicaid has not covered a larger share of poor children because eligibility has generally been linked to the receipt of cash welfare, which has generally been available only to families where the child is deprived of the support of at least one parent. In addition, families have been required to meet State income eligibility standards, which are below Federal poverty guidelines. Congress has recently acted to disconnect the eligibility link between Medicaid and cash welfare for some pregnant women and children. States now are required to extend Medicaid eligibility to some pregnant women and children, and are allowed to extend eligibility to others. States now also have the option to offer short-term Medicaid eligibility to pregnant women so that they can receive prenatal care while their Medicaid applications are being processed. States have some discretion over the Medicaid services they cover. Maternal and Child Health Services Block Grant funds may be used to provide primary care services to mothers and children, particularly those with low incomes or limited access to health services.

Children with chronic conditions are those whose conditions last for a substantial period of time. About 10 to 30 percent of all children are affected by some chronic disorder; most of these children have mild chronic conditions which do not require prolonged and expensive medical treatment. About 1 to 5 percent of all children, however, have chronic conditions which regularly limit their daily life activities to some extent. A subset of the chronically disabled population are those children who must depend on life-sustaining medical technology. Most children with chronic conditions have health care needs which are similar to those of children without chronic conditions; however, some other children, primarily those with disabling conditions, require additional or more intense health care services. These children may have special needs for medical, psychosocial, educational, family support, and coordination services. On average, chronically disabled children use more medical services and have higher health care costs than other children. Disabled children with extremely high medical costs are among those who may be considered to have "catastrophic" health care costs.

Children with chronic disabilities have roughly the same rate of health coverage as other children; however, they are less likely to be covered by private health insurance and more likely to be covered by public health plans. The level of financial protection offered by a health insurance plan may depend on deductible and coinsurance payments, maximum benefit limits, and limits on covered services.

Medicaid can finance health care for disabled children who are poor, but only if the children and their families meet State eligibility standards. States may extend eligibility to the medically needy--those individuals with high medical expenses who would qualify except that their income and resources are just above the eligibility limits. Families with incomes higher than the medically needy limits may become eligible by "spending down," if their medical expenses reduce their incomes below the limits. Some disabled children not otherwise eligible for Medicaid may become eligible while institutionalized; however, until recently, such children rarely would have been eligible for equivalent care at home. Medicaid law now allows States to expand eligibility and increase covered services for the home care of disabled children. Poor children who are disabled are more likely to be covered under Medicaid than other poor children. The type of Medicaid benefits disabled children may receive under Medicaid depend on which services are covered in their State. States may restrict or expand the availability of Medicaid covered services. Other funding sources important to children with chronic conditions include the Maternal and Child Health Services Block Grant, Medicare's End-Stage Renal Disease program, and charitable organizations.

Appendixes at the end of this report provide background information on Federal programs and policies which affect children's health care. Medicaid is a medical assistance program for certain low-income individuals who are aged, blind, disabled, members of families with dependent children, or in specified groups of pregnant women and children. The Maternal and Child Health Services Block Grant provides funding for activities to improve the health status of mothers and children. Medicare's End-Stage Renal Disease program covers individuals, including children, who require kidney dialysis or transplants in order to survive. Federal policies regarding private health insurance include tax policies that help finance health insurance coverage and medical care, and policies that affect the content of health insurance plans.

INTRODUCTION

The attention of policymakers has focused on children's health issues due to a number of factors. One factor is the realization that interventions to improve the health of children not only may benefit children in the short term, but also may enhance their potential to become healthy and productive adults. Missed opportunities to prevent or treat childhood health problems may impose lifetime costs on children, their families, and society. Another factor is a concern by some that not all groups of children have shared equally in the progress made in improving child health. Health status and use of health services vary according to family income, parental education, and race and ethnicity. Finally, government studies have suggested that, despite significant improvements, the United States is not doing as well as it could to promote the health of children. 1/

This report provides background information on health care for children. It is divided into two sections and is accompanied by four appendixes. The first section of this report examines primary care for children--the care provided at the point where the child enters the health care system and receives basic ambulatory services. Relevant issues include the content of primary care services, access to such services, and financing of these services.

The second section of this report examines care for children with chronic conditions--those children with disorders that last for a substantial period of time. Issues important to children with chronic conditions include health care service needs, use and cost of medical services, and financing of services.

Four appendixes at the end of this report provide background information on Federal programs and policies concerning the health of children. While there are many such programs, the information in the appendixes is limited to descriptions of three health programs under the jurisdiction of the Senate Committee on Finance: Medicaid, the Maternal and Child Health Services Block Grant, and Medicare's End-Stage Renal Disease program. 2/ In addition, a final appendix summarizes Federal Government policies, including tax policies, which may affect health insurance coverage of children.

I. PRIMARY CARE FOR CHILDREN

A. Primary Care Services

Primary care is generally the care provided at the point where the child enters the health care system and receives basic ambulatory services. Primary care often involves a continuing relationship between physician (or other medical professional) and patient, even in the absence of disease. It is at this level that the child is integrated into all other aspects of health care. 3/

This is in contrast to secondary and tertiary care. At the secondary level, the patient is provided with specialized ambulatory services and inpatient services in a facility such as a community hospital. At the tertiary level, the patient receives care at the type of medical center which provides highly complex and specialized services generally not available at community hospitals. 4/

Children generally have patterns of illness which are different from those of adults. Children may become ill more often, but their illnesses are generally less serious and are often "self-curing." Of course, some children become very ill, while others develop minor children's illnesses which may turn quite serious if they remain unchecked (e.g., if left unattended, otitis media, recurrent middle ear infection, may result in significant hearing loss).

Children may also face developmental and behavioral problems. Some health analysts maintain that such patterns indicate the need for children's health services to focus on primary care. 5/

Most children require episodic treatment for acute illnesses. Common illnesses include ear infections, upper respiratory infections, sore throats, tonsillitis, and bronchitis. Table 1 lists, based on information from the 1985 National Ambulatory Medical Care Survey, the top 15 principal reasons for children's visits to physicians' offices. According to the survey, there were 118.8 million visits to physicians' offices in 1985.

A smaller number of children require regular care for chronic conditions. The care required by these children is discussed in section II of this report.

TABLE 1. Top 15 Reasons for Visits to Physicians' Offices, a/ By Children Under Age 15, 1985

Rank	Principal reason for visit	Percentage of visits
1	Well-baby exam	13.8
2	Cough	6.6
3	Fever	6.4
4	Earache or ear infection	6.0
5	General medical examination	4.9
6	Throat symptoms	4.9
7	Head cold/upper respiratory infection	3.1
8	Skin rash	3.1
9	Nasal congestion	2.2
10	Physical examination required for school	1.3
11	Vomiting	1.3
12	Allergy not otherwise specified	1.2
13	Otitis media (middle ear infection)	1.2
14	Prophylactic inoculations	1.1
15	Allergy medication	1.1
	All others	41.7

a/ Excludes settings not considered a physician's private office, such as part-time offices, hospital emergency rooms, other hospital outpatient clinics school clinics, and family planning clinics.

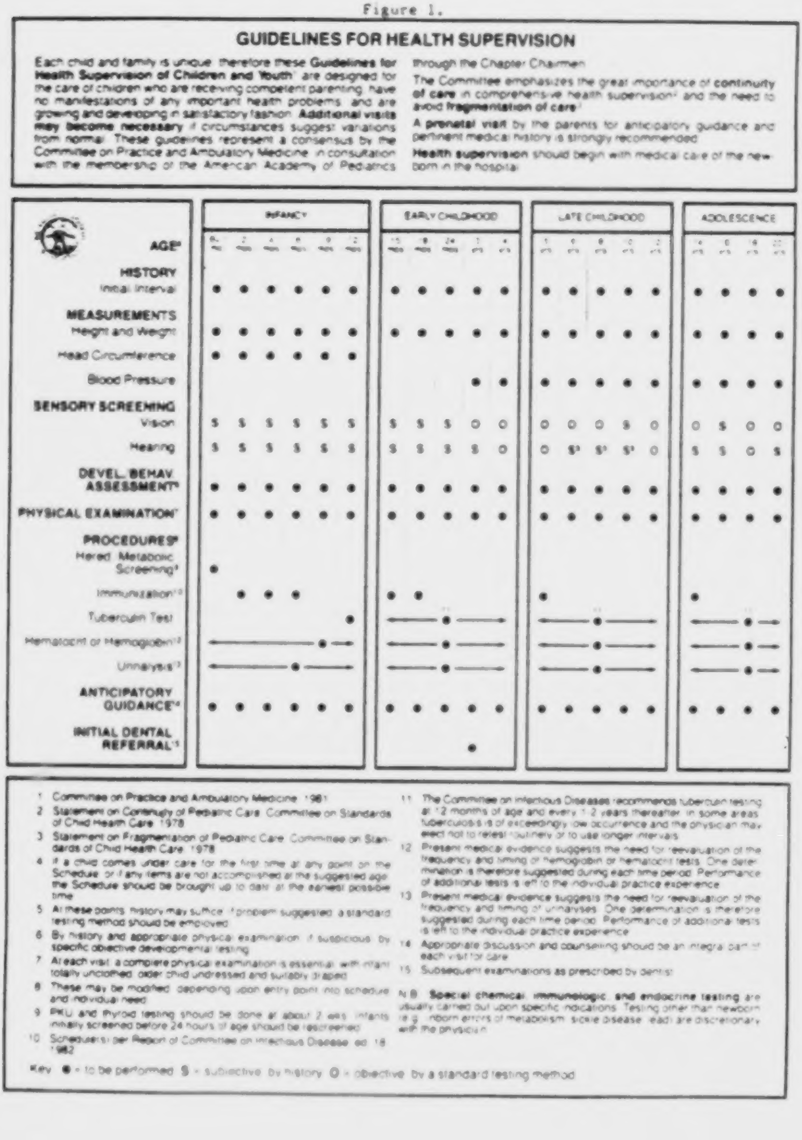
Source: National Center for Health Statistics. Unpublished data from the 1985 National Ambulatory Medical Care Survey.

As table 1 shows, children not only visit physicians' offices for treatment of acute illnesses, but also for preventive health care. According to the American Academy of Pediatrics (AAP), preventive care enables children to achieve optimal physical, intellectual, and emotional growth and development, and offers them a better chance to develop into healthy and productive adults. 6/ Preventive health care for children is designed not only to prevent the occurrence of childhood diseases, but also to prevent those diseases which do occur from becoming more severe and destructive. 7/ For example, infectious diseases may spread further and may result in progressive deterioration if not identified and treated at an early stage. Early diagnosis and treatment of certain orthopedic conditions may reduce the risk and severity of complications. Early detection of certain visual defects may reduce permanent vision problems. 8/

One preventive service of importance to children actually takes place before their birth. Prenatal care has been proven to be an effective way to reduce the incidence of low birth weight, a major determinant of infant mortality. 9/ Adequate prenatal care encourages behavioral changes that improve the mother's health and nutrition (e.g., cessation of smoking or improved diet). It may also uncover medical conditions (e.g., hypertension or iron deficiency anemia) that with appropriate treatment may not be as threatening to the infant's health. 10/ The American College of Obstetricians and Gynecologists (ACOG) recommends that prenatal care begin as early in the first trimester of pregnancy (3 months) as possible. Women with uncomplicated pregnancies should be seen every 4 weeks for the first 28 weeks of pregnancy, every 2 to 3 weeks for the next 8 weeks, and weekly thereafter until delivery. ACOG suggests that women with medical or obstetric problems be seen more frequently. 11/

The AAP's Committee on Practice and Ambulatory Medicine has developed guidelines for health supervision of children and youth. In addition to recommendations on prenatal care, the AAP suggests the following series of preventive well-child visits for most children: six during infancy (under 1 year old), five during early childhood (age 1 to 4), five during late childhood (age 5 to 12), and four during adolescence (beginning at age 14). The care recommended for these well-child visits includes medical histories, measurements, sensory screening, developmental and behavioral assessments, physical examinations, specified procedures, anticipatory guidance, and an initial dental referral. An information sheet describing the AAP guidelines is reproduced in figure 1.

Figure 1.



GUIDELINES FOR HEALTH SUPERVISION

Each child and family is unique; therefore these **Guidelines for Health Supervision of Children and Youth**[1] are designed for the care of children who are receiving competent parenting, have no manifestations of any important health problems, and are growing and developing in satisfactory fashion. **Additional visits may become necessary** if circumstances suggest variations from normal. These guidelines represent a consensus by the Committee on Practice and Ambulatory Medicine, in consultation with the membership of the American Academy of Pediatrics through the Chapter Chairmen.

The Committee emphasizes the great importance of **continuity of care** in comprehensive health supervision[2] and the need to avoid **fragmentation of care**.[3]

A **prenatal visit** by the parents for anticipatory guidance and pertinent medical history is strongly recommended.

Health supervision should begin with medical care of the newborn in the hospital.

	INFANCY						EARLY CHILDHOOD					LATE CHILDHOOD					ADOLESCENCE			
AGE[4]	By 1 mo	2 mos	4 mos	6 mos	9 mos	12 mos	15 mos	18 mos	24 mos	3 yrs	4 yrs	5 yrs	6 yrs	8 yrs	10 yrs	12 yrs	14 yrs	16 yrs	18 yrs	20+ yrs
HISTORY																				
Initial/Interval	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
MEASUREMENTS																				
Height and Weight	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Head Circumference	●	●	●	●	●	●														
Blood Pressure										●	●	●	●	●	●	●	●	●	●	●
SENSORY SCREENING																				
Vision	S	S	S	S	S	S	S	S	S	O	O	O	O	O	S	O	O	S	O	O
Hearing	S	S	S	S	S	S	S	S	S	S	O	O	S[5]	S[5]	S[5]	O	S	S	O	S
DEVEL./BEHAV. ASSESSMENT[6]	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
PHYSICAL EXAMINATION[7]	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
PROCEDURES[8]																				
Hered./Metabolic Screening[9]	●																			
Immunization[10]		●	●	●			●	●				●					●			
Tuberculin Test						●			←●[11]→					←●[11]→					←●[11]→	
Hematocrit or Hemoglobin[12]					←●→				←●→					←●→					←●→	
Urinalysis[13]				←●→					←●→					←●→					←●→	
ANTICIPATORY GUIDANCE[14]	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
INITIAL DENTAL REFERRAL[15]										●										

1. Committee on Practice and Ambulatory Medicine, 1981.
2. Statement on Continuity of Pediatric Care, Committee on Standards of Child Health Care, 1978.
3. Statement on Fragmentation of Pediatric Care, Committee on Standards of Child Health Care, 1978.
4. If a child comes under care for the first time at any point on the Schedule, or if any items are not accomplished at the suggested age, the Schedule should be brought up to date at the earliest possible time.
5. At these points, history may suffice; if problem suggested, a standard testing method should be employed.
6. By history and appropriate physical examination; if suspicious, by specific objective developmental testing.
7. At each visit, a complete physical examination is essential, with infant totally unclothed, older child undressed and suitably draped.
8. These may be modified, depending upon entry point into schedule and individual need.
9. PKU and thyroid testing should be done at about 2 wks. Infants initially screened before 24 hours of age should be rescreened.
10. Schedule(s) per Report of Committee on Infectious Disease, ed. 18, 1982.
11. The Committee on Infectious Diseases recommends tuberculin testing at 12 months of age and every 1-2 years thereafter. In some areas tuberculosis is of exceedingly low occurrence and the physician may elect not to retest routinely or to use longer intervals.
12. Present medical evidence suggests the need for reevaluation of the frequency and timing of hemoglobin or hematocrit tests. One determination is therefore suggested during each time period. Performance of additional tests is left to the individual practice experience.
13. Present medical evidence suggests the need for reevaluation of the frequency and timing of urinalyses. One determination is therefore suggested during each time period. Performance of additional tests is left to the individual practice experience.
14. Appropriate discussion and counselling should be an integral part of each visit for care.
15. Subsequent examinations as prescribed by dentist.

N.B. **Special chemical, immunologic, and endocrine testing** are usually carried out upon specific indications. Testing other than newborn (e.g., inborn errors of metabolism, sickle disease, lead) are discretionary with the physician.

Key: ● = to be performed; S = subjective, by history; O = objective, by a standard testing method

Information on the overall effectiveness of well-child services at improving children's health status is limited. The merit of certain of these practices, such as childhood immunizations, has been established. The level of effectiveness of certain other well-child services, such as regular general physical examinations for children, has not been clearly demonstrated. 12/

B. Access to Primary Care Services

A number of government and academic studies have examined children's access to medical care through the analysis of responses to health care surveys, including the 1980 National Medical Care Utilization and Expenditure Survey (NMCUES). While this survey is somewhat dated and has other limitations, it is among the best national sources of information available for examining the use of medical care among children.

One indicator of children's access to care is the availability of a "regular source" of ambulatory medical care. These sources--including private physicians' offices, group practices, public clinics, and hospital outpatient departments--should provide children with appropriate medical care or referrals. According to NMCUES data, 91.9 percent of all children under age 18 were reported by their parents to have a regular source of care. 13/ It is important to note that some of the parents responding may have reported access to sources such as hospital emergency rooms, which are not generally considered to be adequate or cost-effective sources of regular care for children. 14/ The likelihood of having a regular source varied only slightly by age, and somewhat more by family income level and race or ethnicity. The poor were less likely to have a regular source. Blacks and Hispanics were also less likely to have such a source.

About three-fourths (75.5 percent) of all children reported at least one medical care visit in 1980, according to the same NMCUES analysis; the mean number of visits reported per child was 3.3. There were large differences among age groups; children from 0 to 2 years old had the lowest rate of no visits (8.0 percent) and the highest number of visits per child (5.3 per year). Among income levels, those children whose family incomes were just above the poverty line were less likely to have seen a medical care provider in the past year (33.3 percent had no visits, 2.6 average visits per child) than those children in both better and worse financial circumstances. About one-third of all black (35.0 percent) and Hispanic (33.4 percent) children did not have a medical visit in the previous year, compared to 21.3 percent of white children; the average number of visits per black (2.1 per year) and Hispanic (2.4 per year) child was lower than the number per white child (3.7 per year).

Another 1980 NMCUES analysis shows that the use of medical care also varied according to a child's health insurance status. 15/ Among the low-income children surveyed, those without Medicaid health insurance coverage were more likely to go without a physician visit (32.6 percent) than those with Medicaid coverage (24.8 percent). Those low-income children without any Medicaid coverage who also had no private insurance coverage were even more likely to have no medical visits (36.3 percent).

The analysis also shows that low-income children with Medicaid or private health insurance were likely to see a physician more frequently than those without such coverage. For example, the average number of visits for low-income children covered by Medicaid (2.9 per child) exceeded the average for uninsured low-income children (1.8 per child).

C. Financing Primary Care Services

1. Health Insurance

a. Extent of health insurance coverage. Most U.S. children are covered by health insurance. In 1986, an estimated four-fifths (80.9 percent) of all children under age 18 had some form of health insurance coverage, leaving about one-fifth (19.1 percent) with no insurance source, according to the March 1987 Current Population Survey (CPS). 16/ An analysis of 1986 CPS data by the Office of Technology Assessment (OTA) estimated that the percentage of uninsured children under 13 years old was in the range of 14 to 19 percent. 17/ Health insurance sources included private health insurance plans (primarily employment-based health insurance plans) and government programs (including Medicaid, Medicare, and military health plans).

The percentage of children covered by health insurance was slightly lower than the percentage of the general population. Of the total population, the percentage with health insurance coverage was 85 percent; of the nonaged, about 83 percent were covered, according to Congressional Research Services estimates from CPS data.

b. Sources of insurance. OTA examined the sources of health insurance for children, using CPS 1986 data. Of the 45 million children under age 13 in 1986, about 63 percent were reported to be covered by private health insurance, including parents' employment-based group health plans and policies purchased directly by the family. Another 16 percent had public health insurance coverage--most were covered by Medicaid, but some were covered by Medicare and the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS). An additional 3 percent were covered by a combination of public and private health insurance. 18/

Most children's private health insurance is purchased through their parents' employment-based group plans. As a result, the availability of coverage under an employer plan greatly affects a child's likelihood of obtaining private health insurance coverage at all. A child's coverage under an employment-based plan depends on (1) the employment status of the family head, (2) whether the employer offers a group plan, (3) whether the employment-based plan offers any family coverage, (4) whether the employer subsidizes the cost of the coverage, and (5) whether the child's relationship to the employee allows the child to be declared as a dependent under the plan. 19/ In 1986, 35 percent of employees in medium and large sized firms had fully employer-paid coverage for their dependents. 20/ Background information on public policies, including tax policies, which may affect private health insurance coverage is presented in appendix D.

c. Poverty status. Roughly one-third of all poor children under age 13 are uninsured, according to the 1986 CPS analysis conducted for OTA. Table 2 shows that children from poor families, as well as children from near-poor families (those with incomes between 100 percent and 150 percent of Federal poverty guidelines), were less likely to have health coverage than children from more affluent families. According to the CPS analysis, 61 percent of all children under age 13 reported as uninsured were either from poor or near-poor families. 21/

TABLE 2. Health Insurance Status of Children Under Age 13, By Income Level, 1986

Insurance status	Family income level as a percentage of the Federal poverty level <100%	100% -150%	150% -200%	>200%	All children under age 13
No insurance	33.1%	30.9%	21.2%	9.4%	19.0%
Public only	49.1	13.9	7.1	2.5	15.6
Private only	14.1	51.3	68.3	86.2	62.7
Combination	3.6	3.8	3.4	1.8	2.7

Source: Office of Technology Assessment. Unpublished data from the 1986 Current Population Survey.

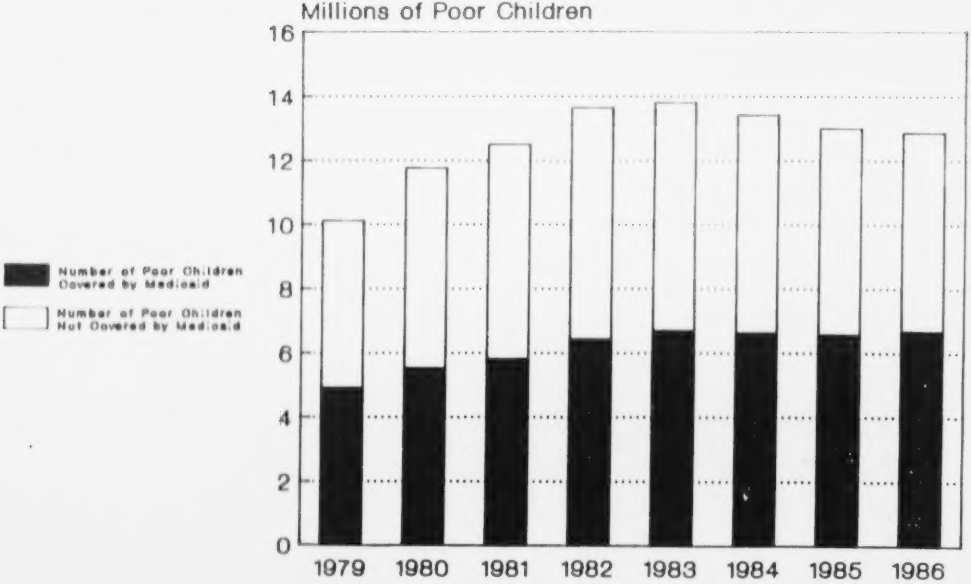
d. Uninsured children. Though most children do have health insurance, concern remains about those who lack this protection. As discussed previously, uninsured children have lower levels of medical care use than children with private or public health insurance coverage. Uninsured low-income children are more likely to have gone without a medical visit in the previous year and are more likely to have seen a physician less frequently than an insured child. 22/ In addition, a larger proportion of expenditures for the uninsured is spent out-of-pocket. 23/ Finally, uninsured children expose their families to the risk of extremely high health care expenses. Under certain circumstances, however, children with such expenses may become eligible for Medicaid (i.e., if the child requires institutional care or if the family's medical expenses reduce their income below the Medicaid income thresholds) or free or discounted medical care (i.e., through public grants, philanthropy, or medical providers). 24/

e. Limitations of coverage. Health insurance coverage may not guarantee full financial protection for the medical needs of children. Some health plans place limits on the benefits covered. For example, some plans may exclude certain types of benefits (e.g., preventive health visits, prescription drugs, dental care, vision care, or outpatient mental health care). Some plans may place limits on the amount and scope of covered benefits (e.g., annual or lifetime limits on all or specified covered benefits). Plans may also exclude coverage for preexisting conditions. Other plans may require waiting periods before services are provided. In addition to benefit limits, health plans may have other features which can expose families to out-of-pocket expenses. For example, some plans require cost-sharing through deductibles (i.e., the amount a family must pay each year before insurance payments begin) and coinsurance (i.e., a percent of the costs for covered services for which the family is responsible). 25/

2. Medicaid Coverage

a. Medicaid coverage of poor children. Roughly one-half of all poor children are covered by Medicaid, according to CPS estimates. Of the 12.9 million children estimated to be in poverty in 1986, 6.7 million were covered. Figure 2 and table 3 show that the percentage of covered poor children was 48.5 percent in 1979. After a decrease to 46.5 percent in 1981, the percentage returned to 48.5 percent in 1983. Since then, the percentage of covered poor children has continually increased to 51.8 percent in 1986. 26/

Figure 2
Number of Poor Children Covered By Medicaid



Source: Current Population Survey, Annual March Income Supplement.
Figure prepared by the Congressional Research Service, Education and Public Welfare Division.

TABLE 3. Medicaid Coverage of Poor Children Under Age 18, 1979-1986

Year	Number of poor children (in thousands)	Number of poor children with Medicaid coverage (in thousands)	Percentage of poor children with Medicaid coverage
1979	10,111	4,907	48.5
1980	11,764	5,525	47.0
1981	12,505	5,811	46.5
1982	13,647	6,429	47.1
1983	13,807	6,693	48.5
1984	13,419	6,622	49.3
1985	13,010	6,569	50.5
1986	12,876	6,676	51.8

Source: Current Population Survey, Annual March Income Supplements.

b. The welfare link. One reason that the share of poor children covered by Medicaid has not been larger in the past is that Medicaid eligibility of such children has generally been linked to the receipt of Aid to Families with Dependent Children (AFDC) cash assistance. 27/ This has restricted Medicaid coverage in part because AFDC assistance has generally been available only to families where the child is deprived of the support of at least one parent (i.e., at least one parent is dead, disabled, continually absent from the home, or, in some States, unemployed). 28/ To receive AFDC benefits, families have also been required to meet income eligibility standards established by each State. AFDC income eligibility thresholds, as of July 1987, ranged from $1,416 in Alabama to $8,988 in Alaska (see table 7 in appendix A). Because State AFDC cash assistance standards have been below Federal poverty guidelines, many poor families with dependent children have not been automatically eligible for Medicaid. 29/ Families often have gained and lost AFDC eligibility during the course of a year.

A legislative provision enacted in 1981 designed to target AFDC cash assistance to those most in need may have denied AFDC assistance, and consequently Medicaid coverage, to additional poor children. Some of these children were able to regain Medicaid protection in those States with medically needy programs; the reduction in the number of eligible children may have also been offset in 1982 by an increase in the number of children who became eligible for AFDC and Medicaid when a recession cut their family incomes.

c. Disconnecting the link. Since 1984, Congress has acted to disconnect the eligibility link between Medicaid and cash welfare for some poor children and pregnant women. As a result, States are now required to provide Medicaid coverage to certain children and pregnant women ineligible for AFDC. In addition, States have also been given the option to cover certain other groups of children and pregnant women and still receive Federal matching funds.

Congress made these changes in response to indications of an erosion in Medicaid's ability to provide access to maternal and child health services. For example, AFDC income thresholds used to determine Medicaid eligibility had not been keeping pace with Federal poverty guidelines. 30/

Policymakers also responded to trends in indicators of maternal and child health status, including infant mortality. After a long period of declining U.S. infant mortality rates, Federal officials expressed concern that the pace of decline was slowing. This slowing decline caused concern for several reasons. Infant mortality rates are one of the most commonly used indicators of a population's health status, and are closely associated with life expectancy levels. The pace of the decline left in doubt whether the nation would meet the U.S. Surgeon General's 1990 goal for reducing the infant mortality rate; it was unlikely that the Surgeon General's goal of reducing the infant mortality rate for all racial or ethnic groups would be achieved. Finally, the U.S. continued to have high levels of infant mortality relative to other industrialized nations. 31/

In addition to interest in improving health status, Congress also expanded Medicaid eligibility in order to support the work efforts of AFDC mothers. Medicaid may present AFDC recipients with work disincentives because Medicaid benefits--coverage of medical expenses--are not varied by income. Because many of those who leave the AFDC rolls lose their automatic eligibility for Medicaid, the extra wage dollar that lifts a family over the AFDC eligibility limit may cause the loss of significant health benefits that are not available from the employer. The value of the medical benefits may put nonworking AFDC recipients in a better financial position than working families. 32/

d. Medicaid eligibility expansions. As a result of the expansion of Medicaid eligibility, all individuals in the following groups are entitled to Medicaid, provided their income and resources fall within State AFDC limits, regardless of family structure or employment status:

- Pregnant women, from medical verification of pregnancy through the month which includes the 60th day postpartum.
- Children born on or after October 1, 1983, up to age 7.
- Former AFDC recipients who lost cash eligibility after 4 months in a job because of the legal requirement that more earnings then be used to offset the AFDC benefit. These recipients are entitled to Medicaid for 9 months after loss of AFDC eligibility, and at State option, for an additional 6 months (previously enacted laws grant some short-term coverage in cases of increased earnings or work hours).

States also have the option to extend Medicaid protection to, and receive Federal matching funds for, the following groups of individuals:

- Children up to age 21 whose family income and resources are at or below the State's AFDC limit, but who do not meet the AFDC definition of dependent children (States are required to cover these children up to age 7, if they are born on or after October 1, 1983).
- Pregnant women and children born on or after October 1, 1983, up to age 8, whose family incomes are at or below 100 percent of Federal poverty guidelines. 33/
- Pregnant women and children up to age 1 whose family incomes are at or below 185 percent of Federal poverty guidelines. 34/

In addition, States have been recently given the option to offer short-term Medicaid eligibility to pregnant women so that they can receive ambulatory prenatal care services while their Medicaid applications are processed. This short-term eligibility period is known as the "presumptive eligibility" period.

For a more precise overview of Medicaid eligibility for the coverage groups listed above (including information on presumptive eligibility), see the description of Medicaid found in appendix A.

e. State responses to coverage options. Federal law requires the States to extend Medicaid eligibility to some of the groups of pregnant women and children described above; however, in other cases, the States have the choice of whether to include particular groups. For example, the Omnibus Budget Reconciliation Act of 1986 (P.L. 99-509, commonly referred to as OBRA86) allows States to extend eligibility to pregnant women--and, on a phased-in basis, young children born on or after October 1, 1983--whose family incomes are at or below 100 percent of Federal poverty guidelines. OBRA86 also allows States to offer short-term presumptive eligibility to certain pregnant women who are waiting for their Medicaid applications to be processed.

Table 4 shows that, as of January 1988, 24 States and the District of Columbia have elected to cover pregnant women and children up to 100 percent of the poverty guidelines, according to the National Governors' Association. Washington State covers these groups up to 90 percent of the poverty guidelines. California did not exercise this option because it already covers these groups within its medically needy income threshold, set at 109.7 percent of the poverty level. Minnesota raised its medically needy threshold in response to the OBRA86 option, and now covers pregnant women and children up to 91.5 percent of the poverty guidelines.

As of January 1988, 12 States have adopted the presumptive eligibility option, according to the National Governors' Association. These States are also listed in table 4.

TABLE 4. State Responses to OBRA86 Coverage Options for Pregnant Women and Children, as of January 1988

	Coverage of pregnant women and children up to specified percentage of poverty	Coverage to age		Presumptive eligibility option	Effective date
		1	2		
Alabama					
Alaska					
Arizona	100		X		1/88
Arkansas	75/100 a/		X	X	4/87
California	b/				
Colorado					
Connecticut	100	X		X	4/88 c/
Delaware	100	X			1/88
District of Columbia	100		X		4/87
Florida	100		X	X	10/87
Georgia					
Hawaii					
Idaho					
Illinois					
Indiana					
Iowa					
Kansas					
Kentucky	100		X		10/87
Louisiana					
Maine				X	
Maryland	100	X		X	7/87
Massachusetts	100		X	X	7/87
Michigan	100		X		1/88
Minnesota	d/				
Mississippi	100		X		10/87
Missouri	100		X		1/88
Montana					
Nebraska					
Nevada					
New Hampshire					
New Jersey	100		X	X	7/87
New Mexico	100		X		1/88
New York				X	
North Carolina	100		X	X	10/87
North Dakota					

See footnotes at end of table.

TABLE 4. State Responses to OBRA86 Coverage Options for Pregnant Women and Children, as of January 1988--Continued

	Coverage of pregnant women and children up to specified percentage of poverty	Coverage to age		Presumptive eligibility option	Effective date
		1	2		
Ohio	100	X			1/89
Oklahoma	100		X		1/88
Oregon	85/100 a/		X		11/87
Pennsylvania	100		X	X	4/88 c/
Rhode Island	100		X		4/87
South Carolina	100	X			10/87
South Dakota					
Tennessee	100		X	X	7/87
Texas					
Utah	100		X	X	4/88 c/
Vermont	100		X		10/87
Virginia					
Washington	90		X		7/87
West Virginia	100		X		7/87
Wisconsin					
Wyoming					
Total	26	5	21	12	

a/ These States will increase their income thresholds to 100 percent of poverty during 1988.

b/ California already covers pregnant women (and all other groups) with family incomes below the Federal poverty guideline by virtue of its medically needy threshold.

c/ Projected implementation date.

d/ In response to OBRA86, Minnesota elected to raise its medically needy threshold to the highest possible percentage (133 1/3 percent) of AFDC payment standards and, as a result now covers all pregnant women with family incomes up to 91.5 percent of the Federal poverty guideline.

Source: National Governors' Association.

f. Covered services. States also have some discretion over the services covered by their Medicaid plans. As described in appendix A, some services must be covered by the States (e.g., prenatal and delivery services for pregnant women and ambulatory care services for children), while others may be covered at State option (e.g., prescription drugs, eyeglasses, and dental care). States may limit the amount, duration, and scope of Medicaid services. The requirement that States provide EPSDT services may help to assure that preventive care and follow-up services are available to children eligible for Medicaid. For a list of Medicaid services covered by State Medicaid plans, see figure 3 in appendix A.

3. The Maternal and Child Health Services Block Grant

Maternal and Child Health (MCH) Services Block Grant funds may be used to provide primary care services to mothers and children, particularly those with low income or limited access to health services. Most of the MCH Block Grant funds are distributed directly to the States; however, a portion of these funds are set aside by the Federal Government for special projects of regional and national significance.

Each State may decide which services its MCH Block Grant funds will be used for. These services may include prenatal care, well-child care, dental care, immunizations, family planning, and vision and hearing screening services. Under the MCH Block Grant, States determine eligibility requirements and have few data collection or reporting requirements. States may charge for MCH Block Grant services (except for those services provided to low income mothers and children) on a sliding scale basis. State agencies which administer the MCH Block Grant programs are also responsible for coordinating the activities between their programs and other related Federal programs, including Medicaid.

In addition to funds designated for the MCH Block Grant's general purposes (which include the provision of primary care services), a specified percentage must be earmarked for programs to develop and promote primary health services. For additional information on the MCH Block Grant, see appendix B.

II. CARE FOR CHILDREN WITH CHRONIC CONDITIONS

A. Children With Chronic Conditions

1. Prevalence of Chronic Conditions in Children

While definitions of chronic conditions vary, most medical experts agree that a chronic condition is one which lasts for a substantial period of time (usually at least 3 months), and in some cases may extend over an entire lifetime. 35/

Estimates of the prevalence of chronic conditions in children range from 10 to 30 percent, depending on the definitions used, populations investigated, and methods of study. When applied to the total population of children in the United States, these rates indicate that approximately 10 to 20 million children are affected by some chronic physical or mental disorder. 36/ Most children with chronic conditions have mild conditions, such as mild cases of allergies, asthma, or acne. Many of the children with mild chronic conditions do not require prolonged and expensive medical treatment. Children may outgrow many of these conditions as they mature.

Some children, however, have chronic conditions which regularly limit their daily life activities. About 10 to 15 percent of children with chronic disorders (i.e., approximately 1 to 5 percent of all children) are estimated to have these disabling disorders. These rates indicate that, depending on the estimate used, about 1 to 3 million children face some degree of disability as a result of their chronic condition. The level of disability ranges from those children limited in their ability to participate in sports or other recreational activities to those children who are disabled to the extent that they cannot attend school (or cannot engage in ordinary play activities if they are of preschool age). 37/

Unlike adult chronic conditions, which are few in number and relatively common (e.g., hypertension, arthritis, diabetes, and coronary artery disease), childhood chronic conditions are numerous and comparatively rare. 38/ Estimates of the prevalence of several chronic conditions in children are displayed in table 5. These estimates include not only those children whose chronic conditions are disabling, but also those who are less severely affected.

TABLE 5. Estimated Prevalence of Chronic Conditions in Children Under Age 21, 1980

Condition	Prevalence estimate per 100,000
Asthma	3,800
(Moderate to severe, 1,000)	
Visual impairment	3,000
(Impaired visual acuity, 2,000)	
(Blindness, 60)	
Mental retardation	2,500
Hearing impairment	1,600
(Deafness, 10)	
Congenital heart disease	700
(Severe, 50)	
Seizure disorder	350
Cerebral palsy	250
Arthritis	220
Paralysis	210
Diabetes mellitus	180
Cleft lip/palate	150
Down's syndrome	110
Sickle cell disease	46
(Sickle cell anemia, 28)	
Neural tube defect	45
(Spina bifida, 40)	
(Encephalocele, 5)	
Autism	44
Cystic fibrosis	20
Hemophilia	15
Acute lymphocytic leukemia	11
Phenylketonuria	10
Chronic renal failure	8
(Nonterminal, 7)	
(Terminal, 1)	
Muscular dystrophy	6
Traumatic brain injury	5

Source: Gortmaker, Steven L. and William Sappenfield. Chronic Childhood Disorders: Prevalence and Impact. Pediatric Clinics of North America, v. 31, Feb. 1984. p. 5.

An analysis of 1980 NMCUES data identifies the following groupings of conditions to be the leading reported causes of disability among children: (1) mental disorders and nervous system disorders, including mental retardation, neurotic and personality disorders, epilepsy, and cerebral palsy; (2) respiratory system diseases, primarily asthma; (3) musculoskeletal and connective tissue diseases, including acquired deformities, arthritis, and other joint disorders; and (4) diseases and disorders of the eyes and ears. These conditions accounted for over half of all conditions reported as main causes of activity limitations. 39/

The study also indicates that the risk of disability varies by age and income. Reports of activity limitations were more common among teenagers and young adults than among young children. Disability was also more likely to be reported among poor children than among children from families with higher incomes.

2. Technology-Dependent Children

A subset of the chronically disabled child population are those children who must depend on life-sustaining medical technology. OTA defines a technology-dependent child as "one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability." 40/

In its study on technology-dependent children, OTA identified the following four groups of children that might be considered technology dependent: (1) children dependent at least part of each day on mechanical ventilators; (2) children requiring prolonged intravenous administration of nutritional substances or drugs; (3) children with daily dependence on other device-based respiratory or nutritional support, including tracheostomy tube care, suctioning, oxygen support, or tube feeding; and (4) children with prolonged dependence on other medical devices that compensate for vital body functions who require daily or near daily nursing care (i.e., those who require infant apnea monitors, renal dialysis, or other medical devices and substantial nursing care in connection with their disabilities).

Table 6 displays OTA estimates for the number of technology-dependent children in each of these groups. The number of children considered to be technology dependent is under 17,000 when limited to the first three categories, but increases significantly when the fourth category (which hospitalization) is included. The number would increase further if the definition included not only those children dependent on medical devices, but also those who require constant or frequent nursing care because of complex drug or therapy needs. 41/

TABLE 6. Summary of OTA Estimates of the Size of the Technology-Dependent Child Population, 1987

Defined population	Estimated number of children
Group 1	
Requiring ventilator assistance	680 to 2,000
Group 2	
Requiring parenteral nutrition	350 to 700
Requiring prolonged intravenous drugs	270 to 8,275
Group 3	
Requiring other device-based respiratory or nutritional support	1,000 to 6,000
Group 4	
Requiring apnea monitoring	6,800 to 45,000
Requiring renal dialysis	1,000 to 6,000
Requiring other device-associated nursing	Unknown, perhaps 30,000 or more

Source: U.S. Congress. Office of Technology Assessment. Technology-Dependent Children: Hospital v. Home Care: A Technical Memorandum. Washington, U.S. Govt. Print. Off., May 1987. p. 4.

B. Services for Children with Chronic Conditions

Children with chronic conditions may have special needs not only for medical services, but also for psychosocial, educational, family support, and coordination services.

1. Medical Services

Most children with chronic conditions have health care needs that are similar to those of children without chronic conditions. Some other children with chronic conditions, however, require additional or more intense health care services than those required by children who are healthy or who have acute illnesses. For the most part, the latter group includes children whose chronic disorders are severe enough to interfere with their daily activities. However, some children with chronic conditions who are not disabled (e.g., certain children with diabetes or hemophilia) require regular primary care services and more frequent hospitalizations for acute illnesses due to their increased risk of infection and serious accident. 42/

The type of services required by these children may include highly specialized medical and surgical services. The children may also require acute and primary care, both specifically for their chronic disorders and generally for diseases unrelated to them. Preventive services, such as early identification and treatment, are particularly important to children with chronic conditions, and may improve long-term outcomes. Other health service needs of this population include home care services and the services of allied health professionals, such as occupational and physical therapy and nursing care.

2. Psychosocial Services

Some chronically disabled children may require psychosocial services. Disabled children and their families have an increased risk of psychological and social problems (although the size of the increased risk is uncertain). Studies indicate that moderately severe chronic conditions often have a more negative psychosocial impact than either mild or very severe conditions; that is, these studies suggest that it may be easier to adjust to a complete disability than to a partial one. In addition, psychosocial impact may be determined by such factors as the disorder's location and cosmetic effects, the child's age, the socioeconomic status and marital stability of the parents, and the support of friends and relatives. 43/

3. Educational Services

The educational needs of disabled children vary according to the chronic disorder which limits their activity. For example, different services would be called for depending on whether a child is mentally retarded, has a specific learning disability, or is blind or deaf. Children with orthopedic problems may require architectural or structural assistance in order to gain access to schools. Secondary effects of chronic conditions, such as missed school days or depression, may also interfere with learning. 44/

The Education for All Handicapped Children Act of 1975 (P.L. 94-142) requires school districts to provide handicapped students with free appropriate public education, including special education and related services. Related services have been defined to include school health, speech therapy, physical and occupational therapy, psychological, counseling, medical diagnosis and evaluation, and parent counseling and training services. While medical services which may be provided only by a licensed physician are excluded from this requirement, other health services which may be performed by a school nurse or other trained health personnel are required. The Education of the Handicapped Act Amendments of 1986 (P.L. 99-457) authorizes funding for early intervention services for infants and toddlers (from birth up to age 3) and their families. As a result of P.L. 94-142 and P.L. 99-457, the financial responsibilities of education agencies and school districts may overlap with those of Medicaid and the Maternal and Child Health Services Block Grant. 45/

4. Family Support Services

The families of children with chronic conditions may require certain support services, such as respite care, support groups, or counseling. The existence of childhood chronic conditions often disrupts family living, by introducing repetitive, demanding, and stressful routines into a family's daily life. For example, urinalysis for children with diabetes, exercise for children with juvenile arthritis, and monitoring for children with autism are required frequently. Parents of children with limited mobility need to provide them with transportation. In addition, families with children who have chronic disorders need to acquire special knowledge of such matters as preparing special diets and securing financial resources. 46/

5. Coordination of Services

Coordination of services is important to children with chronic disabilities. One approach to coordination is case management; under case management one individual or organization is responsible for locating, coordinating, and monitoring all of the medical, social, and educational services needed by the patient. Disabled children may receive services from a large and diverse group of providers (including family physicians, pediatricians, medical specialists, pediatric nurses, physical therapists, social workers) and support from a variety of institutions (such as hospitals, schools, public health programs, and community organizations). These caregivers may have contradictory values, competing interests, and difficulty in communicating with one another. These issues may stand in the way of the coordination of services necessary to develop a comprehensive health care delivery system for chronically ill children. For example, the pediatrician and the medical specialist attending to the child's chronic condition may not coordinate their services, and neither may take primary responsibility for the child's overall health. 47/

C. Use and Cost of Medical Services for Children with Chronic Conditions

1. Use of Medical Services

The use of medical care services by children with chronic disorders varies with the type of condition and its severity. On average, children under age 21 with disabling chronic conditions were more than twice as likely to be hospitalized as children without disabilities, according to 1980 NMCUES data. 48/ Among hospitalized children, disabled children were likely to have hospital stays which were twice as long as other children. As a result, disabled children spent about four times as many days in the hospital as nondisabled children. 49/

The NMCUES data show children with activity limitations also used greater levels of outpatient care. Disabled children visited physicians almost twice as often as others. They were over five times more likely to use the services of nonphysician health professionals, such as nurse practitioners, physical therapists, psychologists, and social workers.

Chronically disabled children received twice the number of prescribed medications and twice the number of specified medical items (including vision aids, orthopedic items, hearing aids, diabetic items, and ambulance or medical transportation services).

2. Cost of Medical Services

The same 1980 NMCUES data were used to estimate health care expenses. 50/ On average, health spending for disabled children under age 21 was nearly three times as high ($1,239, adjusted for inflation by the medical services component of the consumer price index for 1986) as spending for the nondisabled ($429). Of the total $35.7 billion in expenses for children's health services, 11 percent ($3.9 billion, in 1986 dollars) was accounted for by the 4 percent of children who reported activity limitations. 51/

Compared to spending for nondisabled children, spending for disabled children under age 21 was almost three times as high for inpatient hospital services; more than twice as high for physician services; more than six times as high for nonphysician medical professionals; and over twice as high for prescribed medications, and specified medical items (including vision aids, orthopedic items, hearing aids, diabetic items, and ambulance or medical transportation services). In addition, the NMCUES data show that out-of-pocket costs (i.e., those paid directly by the family) were higher for disabled children, even though such costs represented a smaller share of their total expenditures.

Even within the disabled children population, there was a great deal of variation in health care spending. A small proportion of disabled children, primarily those who were hospitalized, accounted for a large share of total spending for disabled children, according to the NMCUES data. When ranked by expenditures, the highest 10 percent of disabled children (with total expenditures exceeding $3,000 in 1986 dollars) accounted for 65 percent of total charges, and the highest one quarter of disabled children accounted for 87 percent of all expenditures. Those disabled children ranked in the bottom half of spending had total expenditures below $250 (in 1986 dollars), primarily for ambulatory services. 52/

Disabled children whose medical costs are at the high end of the spectrum are among those who may be considered to have "catastrophic" health care costs. Such costs usually result from either an episode of acute care brought on by a medical emergency (e.g., a premature delivery or an accident causing extensive burns) or from a long-term pattern of treatments for a chronic condition (e.g., a child who has cystic fibrosis or who is ventilator dependent).

There are several ways to define catastrophic costs, including (1) medical expenses which exceed a fixed amount (e.g., $10,000 per year), including expenses covered by insurance; (2) out-of-pocket expenses which exceed a fixed amount (e.g., $2,000 per year); (3) out-of-pocket expenses which exceed a specified percent of family income (e.g., 10 percent per year); (4) medical expenses which are for the treatment of a specified condition (e.g., cancer); or (5) definitions including components of the above. 53/

D. Financing Services for Children with Chronic Conditions

1. Health Insurance

As discussed in section I of this report, about 81 percent of all children under age 18 are estimated to have some form of health insurance coverage, leaving about 19 percent without such protection. Sources of coverage include both private health insurance (primarily employment-based health insurance) and government programs (such as Medicaid, Medicare, and military health plans). Many of the health insurance issues previously discussed in relation to primary care coverage also apply to the coverage of chronically disabled children; however, due to the high health care costs which families of chronically disabled children may face, there are certain issues of particular interest.

a. Insurance coverage. Disabled children have roughly the same rate of health insurance coverage as other children; however, they are less likely to be covered by private health insurance plans and more likely to be covered by Medicaid or other public plans. Data from the 1984 National Health Interview Survey show that 61.7 percent of children with activity limitations had private insurance coverage only, compared to 71.3 percent of children without limitations. In contrast, 21.4 percent of the disabled had public coverage only, while 12.5 percent of the nondisabled had such coverage. Four percent of the disabled and 1.7 percent of the nondisabled were covered by a combination of both public and private coverage. 54/

The differences in private and public coverage may be explained by differences in employment status of parents, higher cost sharing, unavailability of individual coverage for children with severe disabilities, lack of coverage above maximum lifetime limits, policies which exclude coverage of preexisting conditions, mandatory waiting periods before coverage may take effect, Medicaid eligibility rules which authorize full payments for the costs of institutionalized children, and parental decisions to rely on government programs for health coverage. 55/ Background information on public policies, including tax policies, which may affect private health insurance coverage is presented in appendix D.

b. Limitations of coverage. Even if a disabled child does have health insurance coverage, that coverage does not necessarily guarantee the child's family will be fully protected from the high health care costs they may face. The level of protection may depend on the following characteristics, which can vary from plan to plan:

- Deductible and coinsurance payments. Individuals covered by private health insurance plans are typically responsible for a deductible (i.e., the amount a family must pay each year before insurance payments begin) and coinsurance (i.e., a percent of the costs for covered services for which the family is responsible). Private health insurance plans tend to require higher cost-sharing than public coverage plans, which require either low or no copayments for most services. In some cases, private insurance plans may establish an upper limit on out-of-pocket spending for coinsurance amounts; that is, after the limit has been reached, the insured is eligible for full benefits without paying any further coinsurance. 56/

- Maximum benefit limits. Many health insurance policies include limits (e.g., annual, per episode, or lifetime limits) on the total amount of payments the plan will make on behalf of the insured. OTA examined a series of surveys which indicated that over three-fourths of all plans contained overall plan maximums; more than half of the employees under these plans were subject to lifetime maximum limits of $500,000 or less. Data on Maryland children who require respiratory support showed that they could exceed a $250,000 maximum in about 1 year if hospitalized, or in about 3 years if treated at home. 57/

- Limits on Covered Services. Health insurance policies also include limits on the type or amount of services which are covered (e.g., no coverage for physical therapy services or a limit on the number of covered hospital days). Coverage for home health care services is an important benefit to certain children with chronic disabilities. In 1986, about one-third of all employees of medium and large firms were not covered for home health care benefits. 58/ Even if coverage for home care is available, the plan may restrict the number of nursing visits, impose dollar maximums, or require high cost-sharing. 59/ As a result, some of the home health benefits offered may not adequately cover the needs of a child who requires continual nursing care. 60/ In addition, because health insurance is designed to cover the costs of medical services, it generally does not cover the additional services often needed by disabled children, such as transportation, home renovations, custodial care, or counseling. 61/

2. Medicaid

An alternative to the private financing of health care for chronically disabled children is public financing, particularly through the Medicaid program. Medicaid can be a major source of health care financing for disabled children who are poor, but only if the children and their families meet their State's Medicaid eligibility standards. The type of benefits these children receive depends on which services are covered in their State. While many of the Medicaid issues discussed in section I in relation to primary care coverage are also relevant to the coverage of chronically disabled children, there are some issues regarding Medicaid eligibility and covered services which are particularly important to children with disabling disorders.

a. Medicaid eligibility. As described in appendix A, those eligible for Medicaid include all recipients of public assistance from the Aid to Families with Dependent Children (AFDC) program, most recipients of public assistance from the Supplemental Security Income (SSI) program (which assists the low-income aged, blind, and disabled), and members of other specified groups (such as certain other pregnant women and children). In order to be eligible, individuals must meet not only categorical requirements, but also income and resource requirements.

Medicaid allows the States to extend eligibility to the medically needy--those individuals with high medical expenses who would qualify for Medicaid except that their family income and resources are just above the eligibility limits. Medically needy income levels vary by State, ranging from $2,064 in Tennessee to $10,200 in California per year for a family of three (see table 7 in appendix A). Families with incomes higher than the medically needy limits may become eligible by "spending down," if their medical expenses reduce their incomes below the medically needy limits.

Some disabled children may not qualify for Medicaid, even under medically needy provisions, because the income and resources of their parents are "deemed" to be available to them if they are living in the same household.

Because children receiving institutional care (e.g., care in a hospital, skilled nursing facility, or intermediate care facility) are not considered to be living in their parents' household after the first month of institutionalization, family income and resources are not considered in determining eligibility after the first month.

Because of these eligibility rules, some disabled children not otherwise eligible for Medicaid may become eligible while institutionalized. Until recently, however, such children rarely would have been eligible for equivalent care at home, even if their medical needs could have been appropriately provided there. The following provisions of Medicaid law now allow States to expand eligibility and increase covered services for the provision of home care to disabled children: 62/

- Regular Section 2176 waivers. Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35) allows States to request waivers of selected Federal requirements in order to provide home and community-based services to certain Medicaid recipients who would otherwise require care in an institution. 63/ Under the Section 2176 waivers, States may select targeted populations (i.e., those in specified groups or in specified areas) which would then be subject to broader income eligibility rules and an expanded range of home and community based services (including some services, not primarily medical in nature, which allow these patients to be cared for at home). Groups which may be covered under Section 2176 waivers include (1) the aged and disabled, (2) the mentally retarded and developmentally disabled, and (3) the chronically mentally ill. In order to gain approval for the waiver, States must demonstrate that the costs of the home and community based services will not exceed the cost of institutional care.
- Model Section 2176 waivers for the disabled. HCFA created a separate category of Section 2176 waivers, known as model waivers, to encourage States to provide home and community based services to certain disabled children and adults who would otherwise be eligible for Medicaid only if institutionalized. This may occur as a result of SSI income eligibility rules (i.e., those which would prevent patients living at home from receiving SSI because family income and resources are deemed to be available to them). Under each model waiver, coverage is limited to no more than 200 blind or disabled individuals who would otherwise be ineligible for Medicaid while living at home because of these SSI deeming rules. States may only cover under the waiver those eligible individuals whose estimated home care costs are below their estimated institutional costs.

- State plan amendment for disabled children. In addition to the waiver options, States also have the option to amend their Medicaid plans to extend Medicaid eligibility to certain disabled children who would otherwise be eligible only if they lived in an institution. The State must determine that these children require the level of long-term care provided in an institution, and that their needs can be met appropriately and less expensively at home. Under this provision, only the usual Medicaid services can be offered to these children; that is, special services cannot be extended to only this coverage group. If the State does make this option available to any disabled children, it must allow all children meeting the eligibility criteria to participate, regardless of whether or not they have been institutionalized.

States are also required to extend Medicaid eligibility to certain children for whom Federal adoption assistance or foster care maintenance payments are made under Title IV-E of the Social Security Act. Children receiving Federal adoption assistance are those identified as having special needs, such as those related to a disability. States have the option to cover certain children for whom State adoption assistance payments are made if the child is identified as having special needs. States often provide Medicaid coverage and other benefits to these disabled children as an incentive for families to care for them.

Poor children with activity limitations are more likely to be covered under Medicaid than poor children without any limitations. According to National Health Interview Survey data from 1983 and 1984, 58.7 percent of disabled children had Medicaid coverage, while 43.7 percent of nondisabled children were covered. 64/

b. Covered services. Whether a chronically disabled child's health needs are met by Medicaid may depend on the benefits offered in that child's State. As described in appendix A, some of the Medicaid covered services needed by disabled children are mandated by Federal law, while others are permitted at State option. Among the mandatory services important to chronically disabled children are inpatient and outpatient hospital care, physician services, laboratory and x-ray services, and Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services.

Some of the Medicaid services covered at State option are also important to children with chronic disabilities. As of October 1, 1986, most States provided services in intermediate care facilities for the mentally retarded (48 States and the District of Columbia), services in skilled nursing facilities for patients under 21 (47 States and the District of Columbia), prescription drugs (47 States and the District of Columbia), and prosthetic devices (44 States and the District of Columbia). Certain other services important to disabled children, however, are not offered as universally, including physical therapy (not covered in 15 States); occupational therapy (not covered in 23 States); speech, hearing, and language disorder services (not covered in 18 States); and private duty nursing (not covered in 31 States). 65/ For a list of Medicaid Services covered by State Medicaid plans, see figure 3 in appendix A.

States are allowed to place certain limits on the amount, duration, and scope of covered services, regardless of whether the services are mandatory or optional. For example, a State Medicaid plan may restrict the number of days, number of visits, length of time, or exact type of service covered. Some of these restrictions, such as the annual limit of 12 hospital days in Alabama, may be significant to the care of chronically disabled children. States may also require prior authorization of certain services in order to control their utilization. 66/

States have certain options to expand the Medicaid services available to children. Under the Medicaid EPSDT program, a State may provide services to children even if they are otherwise not available, or available under a limited basis, to other Medicaid beneficiaries (e.g., children may receive vision and hearing services not otherwise available from the State's Medicaid plan). States also have the option of targeting case management services to specified groups of Medicaid beneficiaries, such as certain children, without being required to offer the same services to all other beneficiaries. States may target the case management services to a specific geographical area within the State without being required to make services available throughout the State.

If a State elects to provide Medicaid coverage to the medically needy, it may choose, but is not required, to offer the same services as it provides to the categorically needy. States which cover the medically needy, however, must [illegible] provide a minimum level of services to this coverage group, including ambulatory care service for children and home health services to those individuals entitled to skilled nursing facility services. States which elect to cover services in institutions for mental diseases or in intermediate care facilities for the mentally retarded are required to provide a broader range of services to the medically needy.

3. The Maternal and Child Health Services Block Grant

One of the purposes of MCH Block Grant is to support State programs for children with special health care needs (formerly known as crippled children's services programs).

Just as with Medicaid, programs for children with special health care needs vary widely from State to State. For example, some State programs directly provide covered services, while other programs act primarily as sources of reimbursement for them. Some State programs limit eligibility to children with certain orthopedic and surgical conditions, while others include children with a wider range of medical conditions and children with behavioral or developmental disorders. 67/

Services provided by State programs for children with special health care needs may include screening, diagnosis, surgery and other corrective procedures, and hospital, post-hospital, speech, hearing, vision, and psychological care. 68/ Services may also include support and coordination services (e.g., counseling and case management) and, in some cases, the services provided in State owned-and-operated hospitals for disabled children. 69/

A portion of MCH Block Grant funds are retained by the Federal Government to support special projects of regional and national significance. Among the projects of importance to children with chronic disorders are genetic disease and hemophilia programs. Certain additional MCH Block Grant funds are reserved for projects to screen newborns for sickle-cell anemia and other genetic disorders.

Other MCH Block Grant funds must be earmarked for community-based service networks and case management services for children with special health care needs. These networks are required to coordinate high-quality services located in children's home communities in order to improve health status, functioning, and well-being of these children. Case management services are those which promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services. For additional information on the MCH Block Grant, see appendix B.

4. Medicare's End-Stage Renal Disease Program

Individuals, including children, may become eligible for Medicare benefits if they suffer from end-stage renal disease (ESRD). A person with ESRD is one whose kidneys will not function at a level which will support life. These patients require kidney dialysis or transplantation in order to survive. In 1983, nearly 6,000 ESRD patients under age 25 were enrolled in the Medicare program. Background information on Medicare's ESRD program is presented in appendix C.

5. Charitable Organizations

Although the financial support provided by charitable organizations does not constitute a large share of health care expenditures for children with chronic conditions, these organizations have carved out a specialized financing role. They often focus their activities on one condition or on a group of related conditions. Their activities may include support for biomedical research, promotion of public education (including advocacy), and the direct provision of services and patient education to children and their families. The services provided by charitable organizations often include those that are not usually otherwise reimbursable.[70]

APPENDIX A. MEDICAID

A. Program Description

The Medicaid program, authorized under Title XIX of the Social Security Act, is a medical assistance program designed to improve access to health care services for certain low-income individuals who are aged, blind, disabled, members of families with dependent children, or in specified groups of pregnant women and children. The program reimburses providers for the health care services delivered to Medicaid beneficiaries.

Although Medicaid is financed jointly by the Federal Government and the State governments, it is administered primarily by the State governments. All of the States (except for Arizona which conducts an alternative demonstration program under a waiver of certain Medicaid requirements), the District of Columbia, and the territories operate Medicaid programs.

Each of the State Medicaid plans are subject to certain Federal requirements concerning which services it must offer, which populations it must cover, and which populations it may elect to cover and still receive Federal matching funds. Some States have decided to extend coverage to groups for whom Federal matching funds are not available. The plans vary substantially from State to State; for example, each State plan has some discretion over its eligibility requirements, covered services, and reimbursement levels.

The current Federal Medicaid contribution to the cost of medical services ranges from 50 percent to 79.65 percent, depending on the average per capita income of a State's residents. The Federal matching rate for administrative costs is generally 50 percent, except for certain expenditures which are subject to higher Federal matching rates. The Federal Government's responsibilities for Medicaid are carried out by the Health Care Financing Administration (HCFA) within the Department of Health and Human Services (HHS). According to HCFA estimates, total Medicaid expenditures in FY 1987 were $47.1 billion. The Federal share was estimated at $26.3 billion, while the States spent $20.9 billion.

B. Eligibility

1. Categorically Needy

One of the Federal Medicaid requirements which the States must follow relates to eligibility. Each State participating in the Medicaid program must provide coverage for the "categorically needy."

The States are required to define the categorically needy to include all recipients of public assistance from the AFDC program, most recipients of public assistance from the Supplemental Security Income (SSI) program (which assists the low-income aged, blind, and disabled), and members of other specified groups (such as certain other pregnant women and children).

Aid to Families with Dependent Children. States are required to offer Medicaid to all families receiving AFDC income assistance--generally those families, financially eligible on the basis of income and resources, with children deprived of the support of at least one parent (i.e., at least one parent is dead, disabled, continually absent from the home, or, in some States, unemployed). Most AFDC recipients are therefore poor single women and their children.

If States extend AFDC coverage to groups such as financially eligible two-parent families with unemployed parents, they must also extend Medicaid coverage to them. States are also required to cover certain categories of families deemed to be AFDC recipients even though they do not receive income assistance (e.g., certain working families who formerly received AFDC payments but who recently lost their cash eligibility).

Supplemental Security Income. States are required to provide Medicaid coverage to most recipients of SSI assistance for the aged, blind, or disabled (i.e., all SSI cash recipients in 35 States and the District of Columbia, only those who also meet their State's more restrictive eligibility requirements in 14 States).74/

Other pregnant women and children. The States are required to include the following groups of pregnant women and children within the definition of the categorically needy for the purposes of Medicaid coverage, even if they are not considered eligible for AFDC or SSI:

- Pregnant women whose family income and resources are at or below State AFDC limits, but who are not otherwise eligible for AFDC (e.g., a pregnant woman in a family where both parents live at home and where the principal breadwinner is employed or a first-time pregnant woman who would be eligible for AFDC payments if her child were already born), from medical verification of pregnancy through the month which includes the 60th day postpartum. Coverage for these pregnant women is limited to medical services relating to pregnancy, postpartum, and family planning services.
- Children born on or after October 1, 1983 whose family income and resources are at or below State AFDC limits, but who do not meet the AFDC definition of dependent children (e.g., a child from a

family where both parents live at home and where the principal breadwinner is employed), up to age 7 (or, at State option, age 8).

- Children whose mothers were Medicaid eligible at the child's birth, as long as the mother remains eligible and the child remains in the same household as the mother (i.e., no separate Medicaid application is necessary for such a child), up to age 1 (or, if a child is a hospital inpatient on his or her first birthday, through the end of the inpatient episode).

- Certain children for whom Federal adoption assistance or foster care maintenance payments are made under Title IV-E of the Social Security Act. Children receiving Federal adoption assistance are those identified as having special needs, such as those related to a disability. Effective April 1, 1988, in cases where a child in foster care is a parent of a son or daughter who is in the same home or institution, the son or daughter would be eligible for purposes of Medicaid eligibility.

In addition to these required groups, the States also have the option to include within the definition of categorically needy, and receive Federal matching funds for, the following groups of pregnant women and children:

- Children up to age 18 (or, at State option, 19, 20, or 21) whose family income and resources are at or below State AFDC limits, but who do not meet the AFDC definition of dependent children. States may cover all of these children or may limit coverage to reasonable categories of them (e.g., those in psychiatric hospitals or intermediate care facilities). Because Senator Abraham Ribicoff was responsible for the legislation which established this coverage group, these children are often referred to as "Ribicoff children." As described above, the States are required to cover such children born on or after October 1, 1983, up to age 7 (or, at State option, age 8).

- Pregnant women, and certain young children born on or after October 1, 1983, with family incomes at or below 100 percent of Federal poverty guidelines ($9,300 for a family of three in 1987) and resources not exceeding standards defined by the State (although they may not be more restrictive than SSI resource limits for pregnant women and AFDC limits for children). Current law specifies that States choosing to provide this coverage may only cover children up to age 5 and must phase in which age groups are covered; that is, States currently may only cover such children up to age 2 in FY 1988; up to age 3 in FY 1989; up to age 4 in FY 1990; and up to age 5 in FY 1991 and later fiscal years. Effective July 1, 1988, however, States are permitted to cover all such children up to age 2 (or at State option 3, 4, 5, 6, 7, or 8), as long as they were born on or after October 1, 1983.

- Effective July 1, 1988, pregnant women and children up to age 1 with family incomes at or below 185 percent of Federal poverty guidelines ($17,205 for a family of three in 1987) and resources not exceeding standards defined by the State (although they may not be more restrictive than SSI resource limits for pregnant women and AFDC limits for children). States have the option of imposing limited premiums for this coverage (i.e., the amount of the premium may not exceed 10 percent of the amount by which family income, less child care expenses, exceeds 150 percent of Federal poverty guidelines).

- Certain children for whom State adoption assistance payments are made, if the child is identified as having special needs, such as those related to a disability. As described above, States are required to cover certain children for whom Federal adoption assistance payments are made under Title IV-E of the Social Security Act.

2. Medically Needy

In addition to the categorically needy, States also have the option of providing coverage for the "medically needy." The medically needy are those with high medical expenses who would meet the criteria for categorically needy assistance except that their family income and resources are just above the applicable eligibility level (i.e., a level which varies State by State, but which may not exceed 133 1/3 percent of a State's AFDC income eligibility standard for their family size). Families with income even higher than the medically needy limits may become eligible by "spending down," if their medical expenses reduce their income below the medically needy limits.

The States have the flexibility to include some coverage groups, and not others, within their medically needy programs and still receive Federal matching funds. If a State has any medically needy coverage at all, however, it must include pregnant women and children who, but for their excess income and resources, would be required to be defined as categorically needy.

Thirty-five States and the District of Columbia have elected to provide coverage to the medically needy.

3. State Eligibility Thresholds

Medicaid eligibility thresholds vary from State to State; as a result, children whose family incomes are identical may or may not be eligible for Medicaid benefits depending on which State they live in. Table 7 displays State income eligibility thresholds, as of July 1987, according to the National Governors' Association. The table shows each State's income limits for its (1) AFDC program; (2) medically needy program, if any; and (3) for its program, for certain pregnant women and children with family incomes below 100 percent of the poverty level (as authorized by OBRA86), if any.

AFDC thresholds, as of July 1987, ranged from $1,416 in Alabama to $8,988 in Alaska. Medically needy thresholds ranged from $2,604 in Tennessee to $10,200 in California. As of July 1987, according to the National Governors' Association, 24 States intended to cover pregnant women and children under the OBRA86 option; two other States, California and Minnesota, provided coverage to these groups under their medically needy authority.

TABLE 7. Medicaid Annualized Maximum Allowable Income Thresholds, July 1987 a/

	AFDC family of 3	Percent of Federal poverty guideline ($9,300) b/	Medically needy family of 3	Percent of Federal poverty guideline ($9,300) b/	Pregnant women and children (OBRA86) family of 3 c/	Percent of Federal poverty guideline ($9,300) b/
Alabama	$1,416	15.2	$ ---	---	$ ---	---
Alaska	8,988	77.3	---	---	---	---
Arizona	3,516	37.8	---	---	9,300	100
Arkansas	2,424	26.1	3,300	35.5	6,975	75
California	7,596	81.7	10,200	109.7	10,200	109.7 d/
Colorado	5,052	54.3	---	---	---	---
Connecticut	6,168	66.3	7,500	80.6	9,300	100
Delaware	3,720	40.0	---	---	9,300	100
District of Columbia	4,368	47.0	5,820	62.6	9,300	100
Florida	3,168	34.1	4,308	46.3	9,300	100
Georgia	3,156	33.9	4,200	45.2	---	---
Hawaii	5,892	55.1	5,892	55.1	---	---
Idaho	3,648	39.2	---	---	---	---
Illinois	4,104	44.1	5,496	59.1	---	---
Indiana	3,456	37.2	---	---	---	---
Iowa	4,572	49.2	6,096	65.5	---	---
Kansas	4,596	49.4	5,580	60.0	---	---
Kentucky	2,364	25.4	3,204	34.5	9,300	100
Louisiana	2,280	24.5	3,096	33.3	---	---
Maine	6,696	72.0	6,492	69.8	---	---
Maryland	4,308	46.3	5,004	53.8	9,300	100
Massachusetts	6,600	71.0	8,796	94.6	9,300	100
Michigan	6,480	69.7	6,444	69.3	9,300	100
Minnesota	6,384	68.6	8,508	91.5	8,508	91.5 e/
Mississippi	4,416	47.5	---	---	9,300	100
Missouri	3,384	36.4	---	---	9,300	100
Montana	4,308	46.3	4,848	52.1	---	---
Nebraska	4,200	45.2	5,400	58.1	---	---
Nevada	3,420	36.8	---	---	---	---
New Hampshire	5,832	62.7	6,468	69.5	---	---
New Jersey	$5,088	54.7	$6,792	73.0	$9,300	100
New Mexico	3,168	34.1	---	---	9,300	100
New York	5,964	64.1	7,400	79.6	---	---
North Carolina	3,108	33.4	4,200	45.2	9,300	100
North Dakota	4,452	47.9	5,220	56.1	---	---
Ohio	3,708	39.9	---	---	---	---
Oklahoma	3,720	40.0	5,004	53.8	9,300	100
Oregon	4,944	53.2	6,588	70.8	7,905	85
Pennsylvania	4,380	47.1	5,100	54.8	---	---
Rhode Island	6,036	64.9	7,896	84.9	9,300	100
South Carolina	4,656	50.1	---	---	9,300	100
South Dakota	4,392	47.2	---	---	---	---
Tennessee	4,236	45.5	2,604	28.0	9,300	100
Texas	2,208	23.7	3,204	34.5	---	---
Utah	8,316	89.4	6,012	64.6	9,300	100

See footnotes at end of table.

TABLE 7. Medicaid Annualized Maximum Allowable Income Thresholds, July 1987--Continued a/

	AFDC family of 3	Percent of Federal poverty guideline ($9,300) b/	Medically needy family of 3	Percent of Federal poverty guideline ($9,300) b/	Pregnant women and children (OBRA86) family of 3 c/	Percent of Federal poverty guideline ($9,300) b/
Vermont	$7,236	77.8	$7,404	79.6	$9,300	100
Virginia	3,492	37.5	4,300	46.2	---	---
Washington	5,904	63.5	6,804	73.2	8,370	90
West Virginia	2,988	32.1	3,480	37.4	9,300	100
Wisconsin	6,600	71.0	8,268	88.9	---	---
Wyoming	4,320	46.5	---	---	---	---
Average State	$4,616	49.3	$5,748	61.3 f/	$9,125 g/	98.1

a/ Based on annualized monthly maximum countable income for a family of 3. Under AFDC, the term "threshold" refers to that income limit which determines program eligibility. This can be either a State's AFDC need or payment standard, depending on how each State determines eligibility. A medically needy threshold refers to a State's medically needy protected income level.

b/ Federal poverty guidelines are prepared annually by HHS and are used by a number of Federal programs as eligibility criteria. The guidelines differ somewhat from the poverty threshold used by the Bureau of the Census to determine the number of poor individuals (see Federal Register, v. 52, p. 5340, Feb. 20, 1987). Poverty levels for Alaska and Hawaii differ from other States (Alaska, $11,620 for a family of 3; Hawaii, $10,690 for a family of three).

c/ Effective January 1988.

d/ California already covers pregnant women (and all other groups) with family incomes below the Federal poverty guideline by virtue of its medically needy threshold.

e/ In response to OBRA86, Minnesota elected to raise its medically needy threshold to the highest possible percentage (133 1/3 percent) of AFDC payment standards and, as a result, now covers all pregnant women with family incomes up to 91.5 percent of the Federal poverty guideline.

f/ The percentage represents the average medically needy threshold as a percent of the Federal poverty guideline only for those States which have medically needy programs. If States without medically needy programs were included in the calculation (AFDC levels would represent eligibility thresholds), the percentage would drop significantly.

g/ The percentage represents the average OBRA86 pregnant women income threshold only for those States which have elected to expand such coverage, and includes California and Minnesota.

4. Special Provisions for Certain Groups

Pregnant women. In order to allow pregnant women to receive ambulatory prenatal care services while their applications are being processed, States have the option to cover pregnant women during this period. This short-term eligibility period, known as the "presumptive eligibility" period, begins when a qualified provider determines that a pregnant woman's family income is below State eligibility thresholds. The provider must notify the State Medicaid agency within 5 days of this determination. The pregnant woman must formally apply for Medicaid within 14 days of the determination or risk losing her presumptive eligibility status. The presumptive eligibility period may continue until the formal Medicaid application is accepted or denied, but may not exceed 45 days. States are required to determine Medicaid eligibility within 45 days of the application date.

To be considered qualified to make presumptive eligibility determinations, a provider must (1) be eligible for Medicaid payment; (2) provide outpatient, rural health, or clinic services; (3) receive funds from or participate in certain other Federal programs or participate in a State perinatal program;[75] and (4) otherwise be determined by the State to be capable of making the determinations. States may further limit which providers may be considered qualified.

Medicaid reimbursement and Federal matching rates for services to presumptively eligible women are to be made at the same rate as for other Medicaid recipients. Payment errors for ambulatory prenatal care provided during the presumptive eligibility period are not to be taken into account when determining a State's error rate for the purposes of quality control.

As of January 1988, 12 States have adopted the presumptive eligibility option, according to the National Governors' Association.

Disabled children. For the purposes of determining Medicaid eligibility, the income and resources of parents are generally considered available, within limits, to their disabled dependent children if they live in the same household. However, because children receiving institutional care (e.g., care in a hospital, skilled nursing facility, or intermediate care facility) are not considered to be living in the family household as his or her parents after the first month of institutionalization, family income and resources are generally not a factor in determining eligibility. As a result, many children who otherwise would not be eligible for Medicaid can qualify as disabled under the SSI program, and therefore Medicaid, when they are institutionalized. Until recently, however, such children rarely would have been eligible for equivalent care at home, even if their medical needs could have been appropriately provided there.

States have the option to offer Medicaid services to disabled children, who would be eligible for Medicaid if they lived in an institution, who need the level of long-term care provided in an institution, but whose needs can be met appropriately and less expensively at home. Without waivers of Federal requirements, however, in order to make this option available to any disabled children, a State must do this for all such disabled children in the entire State.

States may request waivers of selected Federal requirements, in order to obtain the flexibility to target coverage for home care services. Such waivers, known as Section 2176 home and community-based services waivers, permit States to limit home and community based projects to qualified disabled individuals in specified groups and in specified areas. In addition, these waivers may authorize the provision of certain services which may not otherwise be available to Medicaid recipients (including some services, not primarily medical in nature, which allow these patients to be cared for at home). See section II for a more complete discussion of Section 2176 waivers.

States are required to extend Medicaid eligibility to certain children for whom Federal adoption assistance or foster care maintenance payments are made under Title IV-E of the Social Security Act. Children receiving Federal adoption assistance are those identified as having special needs, such as those related to a disability. States have the option to cover certain children for whom State adoption assistance payments are made if the child is identified as having special needs. States often provide Medicaid coverage and other benefits to these disabled children as an incentive for families to care for them.

Aliens. Pregnant women and children under age 18 who are aliens participating in the alien legalization process are exempt from a 5-year prohibition of Medicaid coverage which would otherwise apply to those seeking permanent residence status.

In addition, all aliens must be covered for emergency services (including delivery services), regardless of their immigration status, if they would otherwise meet Medicaid requirements.

The homeless. States must cover eligible residents without regard to whether their residence is maintained permanently or at a fixed address. States are required to make eligibility cards available to beneficiaries who do not reside in a permanent dwelling or do not have a permanent home or mailing address.

C. Covered Services

1. Services for the Categorically Needy

Mandatory services. As with eligibility, service coverage is subject to minimum Federal requirements. For the categorically needy, all State Medicaid programs must furnish inpatient and outpatient hospital, rural health clinic, laboratory, x-ray, family planning, physician, and nurse midwife services. Skilled nursing facility services are also required, but only for those age 21 and older.

One service requirement of particular importance to children requires States to provide Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) to all categorically needy recipients up to age 21. Each State's Medicaid program must (1) inform all eligible children about EPSDT services, (2) provide screening and diagnostic services, and (3) provide treatment to correct or ameliorate any discovered health problems.

Each State must provide, at a minimum, the following EPSDT services: assessments of health, developmental, and nutritional status; unclothed physical examinations; immunizations appropriate for age and health history; appropriate vision, hearing, and laboratory tests; dental screening furnished by direct referrals to dentists, beginning at age 3; and treatment for vision, hearing, and dental services found necessary by the screening. Each State is required to have a periodicity schedule which meets reasonable standards of medical and dental practice, as determined by the State Medicaid agency after consultation with recognized medical and dental organizations involved in children's health care. The periodicity schedule specifies which screening services would apply to which stage of a child's life.

States are permitted to provide services to children under EPSDT even if they are otherwise not available, or available on a limited basis, to other Medicaid beneficiaries (e.g., vision, hearing, and dental services that may not otherwise be available from that State's Medicaid program). Spending for EPSDT in 1987 was $139.7 million, according to Administration estimates.

Optional services. States have the option to cover a variety of additional services to their categorically needy recipients. These services include prescribed drugs, eyeglasses, dental care, physical therapy, occupational therapy, skilled nursing facility services, intermediate care facility services, and the services of podiatrists, optometrists, and chiropractors. The optional services covered in each State are shown in figure 3.

Figure 3. Optional Services Covered by State Medicaid Plans, As of October 1, 1986

• CN[2]
+ Both CN and MN[3]

FMAP[1]	Basic Required Medicaid Services See Above		Podiatrists Services	Optometrists Services	Chiropractors Services	Other Practitioners Services	Private Duty Nursing	Clinic Services	Dental Services	Physical Therapy	Occupational Therapy	Speech, Hearing and Language Disorder	Prescribed Drugs	Dentures	Prosthetic Devices	Eyeglasses	Diagnostic Services	Screening Services
[illegible]	•	Alabama		•				•					•		•	•		
[illegible]	•	Alaska		•	•			•	•	•	•	•			•	•		
		American Samoa[4]																
[illegible]		Arizona																
[illegible]	+	Arkansas		+	+	+		+	+				+	+	+	+		
[illegible]	+	California	+	+	+	+		+	+	+	+	+	+	+	+	+	+	+
50.00	•	Colorado	•	•		•		•	•				•			•		
50.00	+	Connecticut	+	+	+	+	+	+	+	+		+	+	+	+	+	+	+
50.00	•	Delaware	•	•		•	•	•					•		•		•	
50.00	+	D.C.	+	+		+	+	+		+	+	+	+		+	+	+	+
[illegible]	+	Florida	+	+		+		+	+			+	+	+	+	+		
[illegible]	+	Georgia	+	+		+		+	+				+	+	+	+		
50.00	•	Guam		•				•	•			•	•			•		
[illegible]	+	Hawaii	+	+		+		+	+	+	+	+	+	+	+	+	+	+
[illegible]	•	Idaho	•	•	•	•		•		•	•		•					
[illegible]	+	Illinois	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	
[illegible]	•	Indiana	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
[illegible]	+	Iowa	+	+	+	+		+	+	+	+	+	+	+	+	+	+	
[illegible]	+	Kansas	+	+	+	+		+	+	+	+	+	+	+	+	+		
[illegible]	+	Kentucky	+	+		+		+	+	+	+	+	+		+	+	+	
[illegible]	+	Louisiana		+				+	+				+	+	+	+		
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50.00	+	Maryland	+	+				+	+	+		+	+	+	+	+		
50.00	+	Massachusetts	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
[illegible]	+	Michigan	+	+	+	+		+	+	+	+	+	+	+	+	+	+	
[illegible]	+	Minnesota	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
[illegible]	•	Mississippi		•					•				•			•		
[illegible]	•	Missouri	•	•				•	•				•	•	•	•		
[illegible]	+	Montana	+	+		+	+	+	+	+	+	+	+	+	+	+	+	+
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[illegible]	•	Nevada	•	•	•	•	•	•	•	•	•	•	•	•	•	•		
[illegible]	+	New Hampshire	+	+	+	+	+	+	+	+	+	+	+		+	+	+	+
50.00	+	New Jersey	+	+	+	+		+	+	+	+	+	+	+	+	+	+	+
[illegible]	•	New Mexico	•	•		•		•	•	•			•	•	•	•		
50.00	+	New York	+	+		+	+	+	+	+	+	+	+	+	+	+	+	+
[illegible]	+	North Carolina	+	+	+			+	+				+	+		+	+	+
[illegible]	+	North Dakota	+	+	+		+	+	+	+	+	+	+	+	+	+	+	+
[illegible]	+	N. Mariana Islands		+				+	+	+			+	+	+	+		
[illegible]	•	Ohio	•	•	•	•	•	•	•	•	•	•	•	•	•	•		
[illegible]	+	Oklahoma	+	+		+		+	+				+		+	+		
[illegible]	+	Oregon	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	
[illegible]	+	Pennsylvania	+	+	+			+	•				•	•	•			
[illegible]	+	Puerto Rico[4]						+										
[illegible]	+	Rhode Island	•	+					+				+	+	+	•		
[illegible]	+	South Carolina	+	+				+	+				+		+	+		
[illegible]	•	South Dakota			•			•	•	•			•	•	•			
[illegible]	+	Tennessee						+		+	+	+	+	+	+	+		
[illegible]	+	Texas	+	+	+	+							+		+	+		
[illegible]	+	Utah	+	+		+		+	+	+		+	+	+	+	+	+	+
[illegible]	+	Vermont	+	+	+	+		+		+	+	+	+		+	+		
50.00	+	Virgin Islands[4]						+					+	+	+	+		
[illegible]	+	Virginia	+	+				+		+	+	+	+					
[illegible]	+	Washington	+	+	•	+	+	+		+		•	+	+	+	+	•	
[illegible]	+	West Virginia	+	+	+	+	+	+	+	+		+	+	+	+	+		
[illegible]	+	Wisconsin		•	•	•	•	+	•	+	+	+	+	•	+	•	•	•
[illegible]	•	Wyoming		•				•		•					•			
•	[illegible]	•	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
+	[illegible]	+	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
	[illegible]	Total	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]

[1] Federal Medical Assistance Percentage (FMAP): Rate of Federal Financial Participation in a State's Medical Assistance Program under Title XIX of the Social Security Act. Effective October 1, 1986 through September 30, 1987, Fiscal Year 1987.

[2] Categorically Needy: Individuals receiving federally-supported financial assistance.

[3] Medically Needy: Individuals who are eligible for medical but not for financial assistance.

[4] American Samoa operates under a special Medicaid waivered program.

The data shown were reported by individual Regional Offices and compiled by the Office of Intergovernmental Affairs.

Figure 3. Optional Services Covered by State Medicaid Plans, As of October 1, 1986--Continued

[illegible]	[illegible]	Services for Age 65 or Older in Mental Institutions			[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	Total Additional Services	
		[illegible]	[illegible]	[illegible]													
●			●	●	●	●				●	●	●	●			[illegible]	AL
		●			●	●	●			●	●	●				[illegible]	AK
																	AS
																	AZ
	●	●	●	●	●	●	●			●	●	●	●			[illegible]	AR
●	●	●	●	●	●	●	●	●	●	●	●	●	●			[illegible]	CA
		●	●	●	●	●	●			●	●		●			[illegible]	CO
●	●	●			●	●	●		●	●			●			[illegible]	CT
		●		●	●	●				●	●					[illegible]	DE
●	●	●	●	●	●	●	●			●	●	●	●			[illegible]	DC
	●	●			●	●			●		●		●			[illegible]	FL
					●	●				●			●			[illegible]	GA
											●					[illegible]	GU
●	●				●	●				●	●	●	●			[illegible]	HI
	●			●	●	●				●	●					[illegible]	ID
●	●	●	●	●	●	●	●		●	●	●		●			[illegible]	IL
●	●	●			●	●	●	●	●	●	●	●	●			[illegible]	IN
●	●	●			●	●	●			●	●					[illegible]	IA
	●	●		●	●	●	●			●	●	●				[illegible]	KS
●	●	●	●	●	●	●	●			●	●		●			[illegible]	KY
	●	●	●	●	●	●	●			●			●			[illegible]	LA
●	●				●	●	●	●	●	●	●	●	●			[illegible]	ME
		●			●	●	●			●	●	●				[illegible]	MD
●	●	●	●	●	●	●	●	●	●	●	●	●	●			[illegible]	MA
	●	●	●	●	●	●	●		●	●	●	●	●			[illegible]	MI
●	●	●	●	●	●	●	●		●	●	●	●	●			[illegible]	MN
					●	●			●	●	●		●			[illegible]	MS
		●			●	●	●					●				[illegible]	MO
●	●	●	●	●	●	●	●			●	●	●	●			[illegible]	MT
		●	●	●	●	●	●			●	●	●				[illegible]	NE
	●	●	●	●	●	●				●	●	●	●			[illegible]	NV
●	●	●		●	●	●		●	●	●	●	●				[illegible]	NH
●	●	●	●	●	●	●	●		●	●	●	●	●			[illegible]	NJ
	●				●	●				●	●		●			[illegible]	NM
●	●	●			●	●	●			●	●	●	●		●	[illegible]	NY
●	●	●		●	●	●	●			●		●	●			[illegible]	NC
●	●	●			●	●	●			●	●		●			[illegible]	ND
											●	●	●			[illegible]	NM
	●	●	●	●	●	●	●		●	●	●		●			[illegible]	OH
	●	●			●	●	●			●		●	●			[illegible]	OK
●	●	●			●	●	●		●	●	●	●				[illegible]	OR
		●	●	●	●	●	●			●	●					[illegible]	PA
																	PR
		●			●	●				●			●			[illegible]	RI
	●	●	●	●	●	●	●			●	●		●			[illegible]	SC
		●	●	●	●	●				●	●	●	●			[illegible]	SD
		●	●	●	●	●	●	●	●	●	●	●	●			[illegible]	TN
	●				●	●			●	●	●	●	●			[illegible]	TX
●	●	●	●	●	●	●	●			●	●	●	●	●		[illegible]	UT
		●			●	●	●			●	●		●			[illegible]	VT
													●			[illegible]	VI
		●	●	●	●	●			●	●	●					[illegible]	VA
●	●	●	●	●	●	●	●			●	●					[illegible]	WA
					●	●	●			●	●					[illegible]	WV
●	●	●			●	●	●		●	●	●	●	●			[illegible]	WI
	●	●			●					●			●			[illegible]	WY
	[illegible]	[illegible]	[illegible]		[illegible]	[illegible]	[illegible]		[illegible]	[illegible]	[illegible]						
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]				
	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]				

[1] Arizona operates a medical assistance program under a Section 1115 Demonstration Project

[2] All services are provided through public health facilities

[3] All services indicated as available to the Medically Needy are not available to all Medically Needy Groups

U.S. Department of Health & Human Services
Health Care Financing Administration
Office of Intergovernmental Affairs

States may also target additional services to Medicaid-eligible pregnant women without being required to provide comparable services to all other beneficiaries. These services may include prenatal, delivery, and postpartum (including family planning) services. States have wide latitude to define which services are considered pregnancy-related.

States have the option to provide case management services on a targeted basis. Case management services are those designed to improve the access of Medicaid recipients to necessary medical, social, and educational services. Under case management, one individual or organization is responsible for locating, coordinating, and monitoring all of the services needed by the patient. If a State targets case management services to a certain group of Medicaid recipients (e.g., certain children), it is not required to offer the same services to all other recipient groups. The State is also permitted to target these services to a specific area of the State without being required to make the services available throughout the State.

States may request waivers of selected Federal requirements in order to implement certain cost-control measures, including those which may be used in conjunction with case management services. Such waivers, known as Section 2175 freedom of choice waivers, could permit States to restrict a recipient's freedom of choice of provider (other than in emergency situations), select Medicaid providers on the basis of cost, modify payment arrangements with certain providers, and operate Medicaid programs that are not necessarily uniform across the entire State. In order for a State to adopt such an approach, the plan must be cost-effective, efficient, and consistent with the purposes of Medicaid.

2. Services for the Medically Needy

If a State's Medicaid program covers the medically needy, it may choose, but is not required, to offer the same services to this group as it provides to the categorically needy. States which cover the medically needy, however, must at least provide a minimum level of services to this coverage group, including prenatal and delivery services for pregnant women, ambulatory services for children under 18, and home health services to those individuals entitled to skilled nursing facility services. State plans which include services in institutions for mental diseases or in intermediate care facilities for the mentally retarded must offer a broader range of services to the medically needy.

3. Demonstration Project

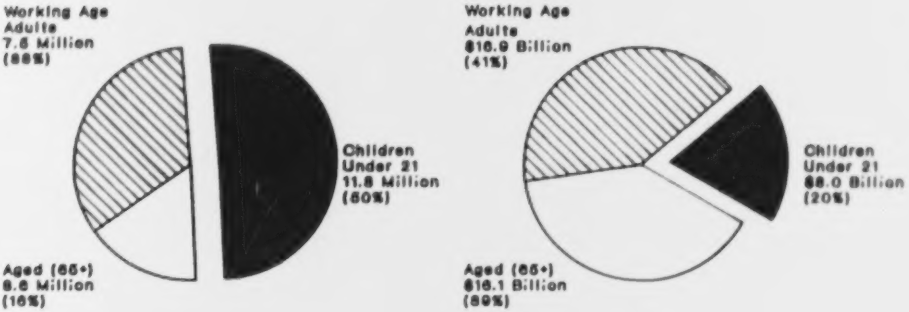
The HHS Secretary may waive certain Medicaid program requirements as necessary in order to conduct demonstration projects. For example, the Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203, commonly referred to as OBRA87) specifically authorizes the Secretary to waive specified program requirements in order to conduct a 3-year demonstration of New York State's prenatal, maternity, and newborn care pilot program as an alternative to existing Federal programs. The Secretary is required to evaluate the project and report to Congress within 1 year of its completion.

D. Share of Medicaid Benefits for Children

One-half of all Medicaid recipients (i.e., those who actually receive Medicaid services) are children. Figure 4 shows that, in FY 1986, 50 percent (11.3 million) of all Medicaid recipients were children under 21. 76/ The next largest group, working age adults, accounted for 33 percent (7.5 million) of the Medicaid population. Those 65 years old and over represented 16 percent (3.6 million) of Medicaid recipients.

Despite the fact that a relatively large share of Medicaid recipients are children, they account for a comparatively small share of Medicaid payments. Figure 4 shows that payments for children were only 20 percent ($8.0 billion) of total Medicaid vendor payments in FY 1985. The two remaining age groups split the remainder of the payments--working age adults accounted for 41 percent ($16.9 billion) and the aged for 39 percent ($16.1 billion).

Figure 4
Medicaid Recipients and Payments, By Age of Recipients, FY 1986



Number of Recipients

Payments

Source: HCFA-2082 forms.
Figure prepared by Congressional Research Service, Education and Public Welfare Division.

APPENDIX B. MATERNAL AND CHILD HEALTH SERVICES BLOCK GRANT

A. Program Description

The Maternal and Child Health (MCH) Services Block Grant, authorized under Title V of the Social Security Act, exclusively supports activities to improve the health status of mothers and children. Most of the MCH Block Grant's funds are distributed directly to State governments; however, a portion of these funds are set aside for use by the Federal Government.

The funds distributed to the States are used to assure access of mothers and children, particularly those with low income or limited access to health services, to quality health services. Other goals of the State programs include reduced infant mortality, reduced incidence of preventable diseases and disabling conditions among children, reduced need for inpatient and long-term care services to children, increased numbers of children (especially preschool children) who are appropriately immunized, and increased numbers of low-income children receiving health assessments and follow-up diagnostic and treatment services. The funds may be used to otherwise promote the health of mothers and children, especially by providing preventive and primary care services for low-income children, and prenatal, delivery, and postpartum care for low-income mothers. MCH Block Grant funds are also used by States to provide specified services for children with special health care needs (formerly referred to as crippled children) or who suffer from conditions leading to this status, and to provide rehabilitation services for certain blind and disabled children under age 16.

States decide which services will be provided with MCH Block Grant funds. These services may include prenatal care, well-child care, dental care, immunization, family planning, and vision and hearing screening services. They may also include inpatient services for children with special health care needs, screening services for lead-based poisoning, and counseling services for parents of sudden infant death syndrome victims. In addition to the responsibility for providing such services, the State agencies which administer the MCH Block Grant programs are also responsible for coordinating the activities between their programs and other related Federal programs. Among these programs are health programs (e.g., Medicaid, particularly its EPSDT component, and family planning programs) and related nutrition, education, and developmental disability programs.

States determine eligibility criteria for the services they provide under the MCH Block Grant. States are allowed to charge for services provided; however, States may not charge mothers and children whose family incomes are below Federal poverty guidelines, and charges must be based on a sliding scale which reflects the income, resources, and family size for those above poverty.

The States have few mandatory data collection or reporting requirements under the MCH Block Grant. While the States are required to report to the Federal Government on how their funds are used, the reports are not required to include any specified data or to be submitted in any particular format. As a result, no consistent data on participation in the MCH Block Grant activities are collected.

Although most of the MCH Block Grant funds are distributed to the State governments, a portion is set aside for use by the Federal Government. These funds are retained by the HHS Secretary to support special projects of regional and national significance (SPRANS), and research, training, and genetic disease and hemophilia programs. These activities are administered by the Health Resources and Services Administration (HRSA) within HHS.

B. Funding

The MCH Block Grant's appropriation for FY 1988 is $526.6 million. A base amount of $478.0 million is allocated differently from funding above that base--$48.6 million in FY 1988.

The base amount. Of the base amount of $478.0 million (an amount equal to the FY 1985 appropriation), 85 percent is distributed to the States, and 15 percent is retained by the Secretary for the general purposes of the MCH Block Grant, as described above.

Amount above the base. Of the $48.6 million appropriated above the base amount, 8 percent is retained by the HHS Secretary specifically for projects to screen newborns for sickle-cell anemia and other genetic disorders. 77/

Of the remaining funds above the base amount (i.e., the other 92 percent of the $48.6 million), two-thirds is allocated in the same way--85 percent to the States, 15 percent to the Secretary--and used for the same general purposes as the base amount.

The other one-third of the remaining funds is similarly allocated into 85 percent and 15 percent shares, but must be specifically earmarked for programs to develop and promote primary health services 78/ for children, and community-based service networks and case management services for children with special health care needs. 79/

Table 8 provides further detail on the allocation of the FY 1988 appropriation for the Maternal and Child Health Services Block Grant.

TABLE 8. Maternal and Child Health Services Block Grant Allocation, FY 1988

	Total allocation	State allocation	Federal allocation
Total appropriation	$526,570,000	$444,281,740	$82,288,260
Base amount a/	478,000,000	406,300,000	71,700,000
Amount above base	48,570,000	37,981,740	10,588,260
Genetic screening b/	3,885,600	0	3,885,600
General purposes a/	29,789,600	25,321,160	4,468,440
Earmarked activities c/	14,894,800	12,660,580	2,234,220

a/ Allocated 85 percent to the State Governments and 15 percent to the Federal Government for use toward the general purposes of the block grant.

b/ Allocated entirely to the Federal Government for newborn screening for sickle-cell anemia and other genetic disorders.

c/ Allocated 85 percent to the State Governments and 15 percent to the Federal Government for use in programs specifically earmarked to develop and promote primary health services for children, and community-based service networks and case management services for children with special health care needs.

Source: Health Resources and Services Administration, Office of Maternal and Child Health.

C. Allocations By State

Of the total appropriation for the MCH Block Grant, $526.6 million in FY 1988, $444.3 million is distributed directly to the States. These funds are allocated among individual States under the two following formulas:

- $422.1 million (an amount equal to the amount distributed to the States in FY 1983) is allocated based upon the proportion of total funding each State received in FY 1981 for certain categorical programs now consolidated under the MCH Block Grant. 80/
- $22.2 million (the amount in excess of the amount distributed to the States in FY 1983) is allocated based on the proportion of low income children in each State to the number of such children nationwide. Data from the 1980 Census are used to determine this proportion.

In order to receive their MCH Block Grant allocation, States must match $3 of their own funds for each $4 in Federal funds received.

Table 9 shows the FY 1988 allocations for the MCH Block Grant by State.

TABLE 9. Maternal and Child Health Services Block Grant Allocations, By State, FY 1988

State	Allocation
Total State Allocations	$444,281,740
Alabama	9,726,041
Alaska	911,066
American Samoa	399,854
Arizona	4,579,092
Arkansas	5,846,070
California	26,355,751
Colorado	6,129,378
Connecticut	4,016,622
Delaware	1,768,145
District of Columbia	6,766,670
Florida	13,291,304
Georgia	13,061,883
Guam	617,552
Hawaii	1,911,104
Idaho	2,767,905
Illinois	17,770,288
Indiana	10,145,333
Iowa	5,871,777
Kansas	3,966,411
Kentucky	9,645,437
Louisiana	10,562,267
Maine	3,073,686
Maryland	10,726,942
Massachusetts	9,944,098
Michigan	15,827,526
Minnesota	8,008,327
Mississippi	8,030,351
Missouri	10,420,285
Montana	2,038,234
Nebraska	3,549,230
Nevada	1,083,654
New Hampshire	1,798,268
New Jersey	9,811,285
New Mexico	3,199,066
New York	33,009,716

TABLE 9. Maternal and Child Health Services Block Grant Allocations, By State, FY 1988--Continued

State	Allocation
North Carolina	13,889,630
North Dakota	1,635,874
Northern Marinas	377,640
Ohio	18,558,668
Oklahoma	5,713,678
Oregon	5,094,950
Pennsylvania	20,744,001
Puerto Rico	12,875,285
Rhode Island	1,394,639
South Carolina	9,797,730
South Dakota	1,977,109
Tennessee	9,585,289
Texas	23,266,559
Trust Territories:	
Palau	119,957
Micronesia	422,068
Marshalls	186,597
Utah	5,359,095
Vermont	1,557,573
Virginia	10,586,378
Virgin Islands	1,212,890
Washington	7,104,022
West Virginia	5,611,217
Wisconsin	9,497,364
Wyoming	1,082,909

Source: Health Resources and Services Administration, Office of Maternal and Child Health.

APPENDIX C. MEDICARE'S END STAGE RENAL DISEASE PROGRAM

A. Program Description

Medicare, authorized under Title XVIII of the Social Security Act, provides health insurance protection for 33 million aged and disabled individuals. Medicare covers hospital services, physician services, and other medical services. The program is administered by the Federal Government. HCFA, an agency within HHS, is responsible for the Medicare program.

Children are generally not entitled to Medicare coverage. Most of the program's beneficiaries are age 65 and older. Those under 65 may become eligible if they are entitled to Social Security or Railroad Retirement disability payments for at least 2 years; however, children are rarely entitled to such payments because they lack the necessary work history.

Certain children, however, may become entitled to Medicare benefits under another eligibility provision. Medicare covers certain individuals, even if they have not reached age 65, if they suffer from end-stage renal disease (ESRD). A person with ESRD is one whose kidneys will not function at a level which will support life. These patients require kidney-dialysis or transplantation in order to survive.

B. Eligibility

Renal disease patients age 65 and older receive coverage for ESRD services under regular Medicare provisions. ESRD patients under 65 are generally eligible for Medicare if they have contributed to the Social Security system for the required length of time, are receiving Social Security benefits, or are spouses or dependents of such individuals. Of all ESRD patients, 93 percent meet these requirements and are therefore eligible for benefits under Medicare. Most of the remaining patients receive coverage from the Veterans Administration and Medicaid programs.

Eligibility for Medicare benefits for ESRD patients generally does not start until the third month after the month in which dialysis treatments begin. Medicare coverage may start earlier, however, in two specific instances.

Coverage may start in the first month of dialysis if an individual enrolls in and is expected to complete a self-dialysis training program. Coverage may start in the first month a patient is admitted to a hospital for a kidney transplant or procedures preliminary to a transplant, as long as the transplant takes place in that month or in the following 2 months.

Entitlement to Medicare ends either 12 months after the month the ESRD patient no longer requires regular dialysis, or 36 months after the month of a kidney transplant. If a transplant fails, and the patient resumes dialysis or receives another transplant, Medicare eligibility may continue or resume immediately without any waiting period.

If an ESRD patient is covered by an employer group health plan, Medicare will generally be a secondary payer for the first year. That is, during the first year, the employer plan first makes payment on the patient's claim; after that, Medicare will only pay for certain costs which are not covered by the employer plan. After the first year, Medicare becomes the primary payer.

Table 10 shows that in 1983, nearly 6,000 ESRD patients under age 25 were enrolled in the Medicare program.

TABLE 10. Medicare End-Stage Renal Disease Program, Enrollment of Beneficiaries Under Age 25, 1983

Age	Enrollment
Total under 25 years	5,734
0-14 years	1,135
15-24 years	4,599

Source: Health Care Financing Administration, Bureau of Data Management and Strategy. Reported in Gornick, Marian, Jay N. Greenberg, Paul W. Eggers, and Allen Dobson. Twenty Years of Medicare and Medicaid: Covered Populations, Use of Benefits, and Program Expenditures. Health Care Financing Review. 1985 Annual Supplement. December 1985. p. 25.

C. Benefits

ESRD beneficiaries are entitled to all Medicare benefits under the Hospital Insurance program (Part A) and the Supplementary Medical Insurance program (Part B), including those related to kidney dialysis and transplantation.

Part A covers inpatient hospital care. In some cases, it also covers short-term skilled nursing facility care after a hospital stay, home health agency visits, and hospice care. Part A helps pay for the costs of an inpatient hospital stay for kidney transplant surgery, including reasonable kidney acquisition costs. Patients are responsible for a deductible ($540 in 1988) each time a hospital admission begins a new benefit period.

Part B covers the services of physicians. It also covers outpatient hospital care, laboratory services, and other medical services and supplies, including immunosuppressive drugs for 1 year after following transplants. Part B covers the services and supplies required for dialysis and most other medical needs of ESRD patients. Patients are responsible for a monthly premium ($24.80 in 1988) and an annual deductible ($75 in 1988). After the deductible is met, Medicare generally pays 80 percent of the approved charges for the program's covered services.

HCFA estimates that $2.4 billion was spent for all Medicare services for all ESRD beneficiaries in 1986.

APPENDIX D. FEDERAL POLICIES REGARDING PRIVATE HEALTH INSURANCE

In addition to its direct expenditure programs for health care, the Federal Government also helps finance the purchase of health insurance coverage and medical care through tax exclusions, deductions, and credits. Such tax subsidies for health care in FY 1989 were estimated in the President's FY 1989 Budget to be $41.3 billion. Among the tax subsidies are those which encourage the purchase of employment-based health coverage.

Public policies have an impact not only on the amount of health coverage purchased, but also on its content. Private health care plans are subject to a variety of laws and regulations.

The following summarizes significant Federal policies regarding private health insurance, particularly as they affect maternal and child health.

A. Federal Tax Subsidies

1. Exclusion for Employer-Provided Health Coverage

All employer contributions for employer-provided health and accident coverage are excluded from the employee's taxable income. Also excluded from taxable income are the benefits received by an employee, or the employee's spouse or dependent, under an employer's health or accident plan to reimburse for medical expenses or to compensate for permanent injury. Provisions for self-employed individuals are discussed next. Employer-provided health plans are required to meet a series of tests to determine if they discriminate in favor of highly compensated employees. In the case of a health plan that fails these tests, the highly compensated employees must include the value of the portion considered to be discriminatory in their taxable income.

2. Deduction for Health Insurance Costs of the Self-Employed

Individuals who are self-employed may deduct 25 percent of their expenses for health insurance. Such expenses may include those for the health insurance of the self-employed individual, as well as for the health insurance of the individual's spouse and dependents.

The deduction, however, may not be larger than the self-employed individual's earned income and may not be taken during a year in which the individual is eligible to participate in an employer-subsidized health plan (including a spouse's plan). The deduction is not allowed unless nondiscrimination requirements, similar to those for employer-provided health plans, are satisfied. The deduction is also not allowed unless health insurance coverage is provided to all employees in unincorporated trades or businesses in which the self-employed individual is a 5 percent owner.

The amount deducted by a self-employed individual under this provision may not also be deducted as unreimbursed medical expenses (or taken into account for the purposes of meeting the 7.5 percent medical expense threshold). In addition, the amount deducted under this provision is not taken into account in computing net earnings from self-employment, and therefore does not reduce the income base for the self-employed individual's Social Security tax. This deduction does not apply after 1989.

3. Deduction for Unreimbursed Medical Expenses

Individuals who itemize deductions may deduct any qualified unreimbursed medical expenses which exceed 7.5 percent of their adjusted gross incomes. Such expenses may include those for the medical care of the taxpayer, as well as for the care of the taxpayer's spouse and dependents.

Medical care expenses which may be deducted are those for (1) health insurance, including employee contributions to employer health plans; (2) diagnosis, treatment, or prevention of disease or malfunction of the body; (3) transportation primarily for and essential to medical care; and (4) lodging away from home primarily for and essential to medical care, up to $50 per night. The costs of prescription medicines and insulin are eligible medical care expenses.

Expenses paid for the general improvement of health, such as fees for exercise or weight-reduction programs, are not eligible for deduction unless prescribed by a physician to treat a specific illness or physical defect.

4. Other Federal Tax Subsidies

Other Federal tax expenditures relating to health care include exclusions of interest on State and local debt for nonprofit health facilities, deductions for contributions to health care charities, and credits for the clinical testing of orphan drugs.

B. Requirements on Employers and Health Insurance Plans

1. State Regulation of Private Health Insurance

The Federal Government has traditionally left the regulation of the content of private health insurance to the States. For many years, insurance was considered to be an activity other than commerce and therefore not subject to Federal regulation. A 1944 Supreme Court decision, however, reversed the Court's traditional position by including insurance within the definition of commerce. Congress responded to the resulting confusion within the insurance industry by passing the McCarran-Ferguson Act of 1945 (P.L. 79-15). This Act clarified congressional intent that States should continue to exercise primary responsibility for regulating the business of insurance.

All 50 States have passed laws requiring health insurance plans to include certain benefits. Some of these requirements are related to maternal and child health care. For example, State laws may require plans to include such services as in vitro fertilization, maternity care, or preventive well-child services. Other State laws may require certain providers (e.g., outpatient birthing centers) to be eligible to be reimbursed for covered services. In addition, State laws may expand the length of time coverage will be in effect (e.g., continuing coverage for an employee and the employee's family in the event the employee is laid off). Finally, State laws may expand the types of individuals (e.g., adopted children) covered under insurance policies.

2. Federal Regulation of Employee Welfare Benefit Plans

While the regulation of insurance has been left largely to the States, employee welfare benefit plans are governed by the Federal Government under the Employee Retirement Income Security Act of 1974 (P.L. 93-406, commonly referred to as ERISA). 81/

Included under the definition of employee welfare benefit plans under ERISA are self-insured health plans. Under such plans, employers assume the risk for the medical care costs of their employees (i.e., this is in contrast to conventional health insurance plans, where employers purchase coverage from either commercial insurance carriers or Blue Cross/Blue Shield plans).

Because self-insured health plans are considered benefits rather than insurance, they are exempt from the State mandates which apply to conventional health insurance plans. Although ERISA regulates such aspects of self-insured plans as disclosure requirements, a great deal of employer discretion remains over the structure of their plans. If employees are represented by a union, their benefits are also subject to the collective bargaining process.

3. Federal Pregnancy Discrimination Provisions

Another Federal requirement, the Pregnancy Discrimination Act of 1978 (P.L. 95-555), requires health plans offered by employers to cover pregnancy-related care (except for abortion) to the same extent as they cover other medical care. P.L. 95-955 applies to employees and their spouses covered under either self-insurance health plans or conventional employment-based health insurance plans.

The provisions of the Pregnancy Discrimination Act of 1978, however, do not extend to pregnant women who are (1) covered by health insurance policies that are not employment-based; (2) covered by health insurance policies offered by firms with 15 or fewer employees; or (3) nonspouse dependents, including teenage daughters, of covered employees. States may enact legislation to extend the provisions of P.L. 95-955 to these groups; however, such extensions would not apply to pregnant women covered under health plans offered by self-insured employers.

4. Federal Continuation of Coverage Provisions

Another Federal requirement, Title X of the Consolidated Omnibus Budget Reconciliation Act of 1985 (P.L. 99-272, commonly referred to as COBRA), has an important impact on health care for children. Title X of COBRA requires certain employers to offer employees and their dependents, who would otherwise lose existing coverage due to changes in employment or family status, the option of purchasing continued group health insurance coverage. COBRA does not require employers to provide health insurance, but it does place certain requirements on those who do.

The COBRA provisions apply if employees or their dependents lose coverage as a result of termination or reduction in hours of employment (other than for reasons of gross misconduct), death, divorce, eligibility for Medicare, or the end of a child's dependency under a parent's health insurance policy. The provisions have been modified to include retirees in cases where the employer files for bankruptcy.

When workers lose coverage as a result of termination or reduction in hours of employment, coverage for them and their qualified dependents must continue for 18 months. For all other qualifying events, coverage must continue for 36 months. Employers are not required to make contributions for such coverage; they may charge the beneficiaries a premium not exceeding 102 percent of the premium that would otherwise apply.

The COBRA continuation provisions apply only to those employers with 20 or more employees who offer group health insurance plans. The provisions apply to State and local governments, but not to the Federal Government or churches. They apply to both employers that offer self-insured plans and those that purchase health insurance coverage.

Failure to provide continued health coverage could result in the loss of tax exclusions and deductions for employer contributions to their employees' health insurance. General enforcement provisions of ERISA apply to those group health plans under its authority. COBRA's provisions are also applied to group health plans maintained by those State or local governments that receive funds under the Public Health Service Act.

Traditionally, many Americans have lost access to private health insurance coverage as a result of changes in employment or family status. For example, employees and their families may have lost coverage under an employer's group health insurance plan if the employee was laid off. Similarly, an employee's dependents may have lost their group coverage if the employee died. Women have been particularly vulnerable to the consequences of such changes. They may have lost coverage not only as a result of the death, unemployment, retirement, or Medicare eligibility of a spouse, but also as a result of divorce or separation. Health insurance coverage of dependent children has also been affected by both the employment or marital status of their parents. In addition, children may have also lost their group plan coverage when they exceeded the maximum age for dependent coverage under their parent's health insurance policy.

1/ Select Panel for the Promotion of Child Health. Better Health for Our Children: A National Strategy. Volume I: Major Findings and Recommendations. Washington, U.S. Govt. Print. Off., 1981. p. 1-2, 25-26.

U.S. Congress. Office of Technology Assessment. Healthy Children: Investing in the Future. Washington, U.S. Govt. Print. Off., 1988. p. 3.

2/ There are many other Federal health programs which have a significant effect on the health of children. These include the Childhood Immunization program; the Community Health Centers; the Family Planning program; the National Institute of Child Health and Human Development; the Alcohol, Drug Abuse, and Mental Health Block Grant; the Preventive Health and Health Services Block Grant; the Indian Health program; the Migrant Health program, the Federal Employees Health Benefits program, and various military health care programs.

In addition, even though they are not strictly characterized as health programs, certain other Federal programs (e.g., those intended to improve nutrition or to provide services to the developmentally disabled) also have an important impact on the health of children.

This report does not contain information on these other programs; however, Federal Programs Affecting Children (CRS Report No. 87-306 EPW) does provide detailed descriptions of health, income, nutrition, social service, education, housing, and tax programs of particular relevance to children.

3/ U.S. Department of Health Education and Welfare. The Education of Physicians for Primary Care. Prepared by Joel J. Alpert and Ewan Charney. (DHEW Pub. No. (HRA) 74-3113). Washington, 1973. p. 1-3.

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Capron, William. Issues of Organization and Financing of Delivery Systems. In Harvard Child Health Project Task Force. Developing a Better System for Child Health. Cambridge, Massachusetts, Ballinger Publishing Company, 1977. p. 4.

4/ Parker, Alberta W. The Dimensions of Primary Care: Blueprints for Change. In Spyros Andreopoulos, ed. Primary Care: Where Medicine Fails. New York, John Wiley & Sons, 1974. p. 18.

5/ Harvard Child Health Project Task Force. Toward a Primary Medical Care System Responsive to Children's Needs. Cambridge, Massachusetts, Ballinger Publishing Company, 1977. p. 1, 7-8.

6/ American Academy of Pediatrics. Committee on Standards of Child Health Care. Standards of Child Health Care. 3rd ed. Evanston, Illinois, American Academy of Pediatrics, 1977. p. 9.

7/ Harvard Child Health Project Task Force, Toward a Primary Medical Care System Responsive to Children's Needs, p. 1-2.

8/ American Academy of Pediatrics. Unpublished materials.

9/ Institute of Medicine. Committee to Study the Prevention of Low Birthweight. Preventing Low Birthweight. Washington, National Academy Press, 1985. p. 37.

10/ Griffith, Jeanne E., and Joseph A. Cislowski. Infant Mortality: Are We Making Progress? Congressional Research Service Review, Jan. 1986. p. 13.

11/ American College of Obstetricians and Gynecologists. Committee on Professional Standards. Standards for Obstetric-Gynecologic Services. Washington, 1985.

12/ Office of Technology Assessment, Healthy Children, p. 119-135.

13/ Butler, John A., William D. Winter, Judith Singer, and Martha Wenger. Medical Care Use and Expenditure Among Children and Youth in the United States: Analysis of a National Probability Sample. Pediatrics, v. 76, Oct. 1985. p. 497.

14/ Office of Technology Assessment, Healthy Children, p. 53-54.

15/ Rosenbach, Margo L. Insurance Coverage and Ambulatory Medical Care of Low-Income Children: United States, 1980. National Medical Care Utilization and Expenditure Survey. Series C, Analytical Report No. 1. DHHS Pub. No. 85-20401. National Center for Health Statistics, Public Health Service. Washington, U.S. Govt. Print. Off., Sept. 1985. p. 15.

16/ These Congressional Research Services estimates are based on data obtained annually from the Current Population Survey (CPS) conducted by the Bureau of the Census. Because the estimates are based on a sample, they may differ somewhat from the figures that would have been obtained if a complete census had been taken. CPS may also underestimate private health insurance coverage of those children who are covered through a noncustodial parent. No adjustments have been made for underreporting of insurance. While these considerations must be taken into account, general trends can be observed from the data.

17/ These estimates include adjustments for underreporting of insurance for those children covered through noncustodial parents.

Office of Technology Assessment. Healthy Children, p. 58.

18/ Office of Technology Assessment, Healthy Children, p. 57-58.

19/ Rosenbaum, Sara. Children and Private Health Insurance. In Schlesinger, Mark, ed. Children in a Changing Health Care System. John Hopkins University Press, forthcoming.

20/ U.S. Department of Labor. Bureau of Labor Statistics. Employee Benefits in Medium and Large Firms, 1986. Washington, U.S. Govt. Print. Off., June 1987. p. 31.

21/ Office of Technology Assessment, Healthy Children, p. 58.

22/ Butler, et al., Medical Care Use and Expenditure Among Children and Youth in the United States, p. 498-499.

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23/ Kasper, Judith D. Children at Risk: The Uninsured and the Inadequately Insured. Presented at the Annual Meetings of the American Public Health Association, Maternal and Child Health Section. Las Vegas, Nevada, Sept. 1986. p. 11.

24/ Office of Technology Assessment, Healthy Children, p. 58-59.

25/ Rosenbaum, Children and Private Health Insurance.

Office of Technology Assessment, Healthy Children, p. 59-60.

26/ These Congressional Research Service estimates of Medicaid coverage of poor children are based on CPS data collected annually by the Bureau of the Census. Because the estimates are based on a sample, they may differ somewhat from the figures that would have been obtained if a complete census had been taken. CPS data on Medicaid are lower than program data from HCFA because recipients tend to underreport their benefits in these surveys. Respondents may also underreport their sources and amounts of income. Poverty status is based on total cash income, including welfare income; Medicaid eligibility is based on income prior to receipt of welfare benefits. The CPS totals do not include children in institutions. While these considerations must be taken into account, general trends can be observed from the data.

27/ For a complete description of Medicaid eligibility, see appendix A.

28/ The States, however, have had the option to extend Medicaid coverage to certain other children, including those known as "Ribicoff children," whose family income and resources are at or below the State's AFDC limit, but who do not meet the AFDC definition of dependent children.

In order to simplify the language in this report, the District of Columbia will at times be referred to as a State.

29/ Some of these children, however, may have been able to obtain coverage through State medically needy programs. The medically needy are those individuals with high medical expenses who would qualify for Medicaid except that their family income and resources are just above the eligibility limits.

30/ Hill, Ian T. Broadening Medicaid Coverage of Pregnant Women and Children: State Policy Responses. Washington, National Governors' Association, Feb. 1987. p. 1.

31/ Griffith and Cislowski, Infant Mortality, p. 12.

32/ Cislowski, Joseph A. Current Welfare System: Expanded Medical Care. Congressional Research Service Review, July 1987. p. 8.

33/ The upper age limit applied to this coverage group is effective July 1, 1988.

34/ Effective July 1, 1988.

35/ Perrin, James M. Introduction. In Hobbs, Nicholas, and James M. Perrin, eds. Issues in the Care of Children with Chronic Illness. San Francisco, Jossey-Bass Publishers, 1985. p. 2.

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36/ Gortmaker, Steven L. and William Sappenfield. Chronic Childhood Disorders: Prevalence and Impact. Pediatric Clinics of North America, v. 31, Feb. 1984. p. 3-4.

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37/ Newacheck, Paul W. The Costs of Caring for Chronically Ill Children. Business and Health, v. 4, Jan. 1987. p. 1-2.

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41/ Office of Technology Assessment, Technology-Dependent Children, p. 3-4.

42/ Fact Book on the Chronically Ill Child Population, p. 6.

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43/ Iryes, Health Care for Chronically Disabled Children and Their Families, p. 327.

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44/ Iryes, Health Care for Chronically Disabled Children and Their Families, p. 328.

45/ U.S. Library of Congress. Congressional Research Service. Education of the Handicapped. Issue Brief No. 74108, by Charlotte Jones Fraas, Washington, Oct. 16, 1986 (archived). p. 1-2, 11-12.

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46/ Iryes, Health Care for Chronically Disabled Children and Their Families, p. 329-330.

47/ Iryes, Health Care for Chronically Disabled Children and Their Families, p. 334.

48/ The NMCUES data may underestimate the use of health care services by chronically disabled children. Underestimates may occur because the survey is designed to measure the use of health care services by the entire population, not the use of special services by disabled children. As a result, NMCUES data do not include data on the use of certain specialized items and services provided to the disabled and do not measure the care provided in institutions. Another result is that the size of the NMCUES sample may be too small to detect rare chronic conditions. In addition, because the NMCUES data were gathered in 1980 and 1981, they do not reflect recent trends in health care financing and delivery (e.g., lower hospitalization rates for children, increased out-of-pocket costs, or increased substitution of outpatient services for inpatient services). The alternatives to these general national surveys are studies which are limited to States or local areas, or which focus on particular conditions; however, such studies are difficult to make generalizable to broader populations.

49/ Newacheck, The Costs of Caring for Chronically Ill Children, p. 19-20.

Newacheck and McManus, Financing Health Care for Disabled Children.

50/ Newacheck and McManus, Financing Health Care for Disabled Children.

51/ Because NMCUES underestimates health services expenditures for chronically disabled children, the data are better used to gain an understanding of general expenditure trends than to determine exact spending amounts.

52/ Newacheck and McManus, Financing Health Care for Disabled Children.

Newacheck, The Costs of Caring for Chronically Ill Children, p. 22-23.

53/ McManus, Margaret A. Catastrophic Childhood Illness: A Briefing Report. American Academy of Pediatrics, May 1986, p. 1.

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54/ Fact Book on Chronically Ill Children's Insurance in the Current Health Care Insurance Market. In Briefing Memoranda for Meeting on the Feasibility of High Risk Pools to Provide Health Insurance Protection for Children with Special Health Care Needs. Washington, Sponsored by the American Academy of Pediatrics, the Bureau of Maternal and Child Health, the March of Dimes, and the National Association of Insurance Commissioners, Dec. 14 and 15, 1987. p. 4.

55/ Taylor, Ann B., Susan G. Epstein, and Allen C. Crocker. Reformulating Health Policy on Behalf of Children with Special Needs and Their Families. In Schlesinger, Mark, ed. Children in a Changing Health Care System. Johns Hopkins University Press, forthcoming.

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56/ Fact Book on Chronically Ill Children's Insurance in the Current Health Care Insurance Market, p. 15.

57/ Office of Technology Assessment, Technology-Dependent Children, p. 52-53.

58/ U.S. Department of Labor. Bureau of Labor Statistics. Employee Benefits in Medium and Large Firms, 1986. Washington, U.S. Govt. Print. Off., June 1987. p. 34-35.

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62/ U.S. Library of Congress. Congressional Research Service. Medicaid "2176" Waivers for Home and Community-Based Care. Report No. 85-817 EPW, by Carol O'Shaughnessy and Richard Price. Washington, 1985. p. 1-5, 16-17.

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63/ The Consolidated Omnibus Budget Reconciliation Act of 1985 (P.L. 99-272) and the Omnibus Budget Reconciliation Act of 1986 (P.L. 99-509) clarified that Section 2176 waivers applied to ventilator-dependent and other patients who would otherwise require hospital-level care.

64/ Newacheck, Paul W. Unpublished data from the National Health Interview Survey, 1983 and 1984 combined annual averages.

65/ U.S. Department of Health and Human Services. Health Care Financing Administration. Office of Intergovernmental Affairs. Medicaid Services State by State. HCFA Pub. No. 02155-87. Oct. 1, 1986.

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66/ Fox, Harriette B., with Ruth Yoshpe. Medicaid Financing for Early Intervention Services. Washington, Fox Health Policy Consultants, June 1987. p. 23.

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67/ Iryes, Henry T., and Richard J. Eichler. Program Priorities of Crippled Children's Agencies: A Survey. Public Health Reports, v. 103, Jan.-Feb. 1988. p. 77.

68/ U.S. General Accounting Office. Maternal and Child Health Block Grant: Program Changes Emerging Under State Administration; Report to the Congress by the Comptroller General of the United States. GAO/HRD-84-35, May 7, 1984, Washington, 1984. p. 28.

69/ Office of Technology Assessment, Technology-Dependent Children, p. 70.

70/ Butler et al., Health Care Expenditures for Children with Chronic Illnesses, p. 844-845.

74/ The States using more restrictive criteria than SSI standards to determine Medicaid eligibility are Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, Nebraska, New Hampshire, North Carolina, North Dakota, Ohio, Oklahoma, Utah, and Virginia.

75/ Specifically, the provider must receive funds from the Migrant Health Centers, Community Health Centers, or Maternal and Child Health Services Block Grant programs; participate in the Special Supplemental Program for Women, Infants, and Children (WIC) or the Commodity Supplemental Food Program; or participate in a State perinatal program.

76/ The data on Medicaid recipients and payments are obtained from HCFA-2082 forms (Statistical Report on Medical Care: Recipients, Payments, and Services). Statistics provided on these forms represent the bills paid within the fiscal year and not necessarily the services rendered in that year. All percentages are based on unduplicated totals. FY 1986 data are the most recent available from these forms.

The HCFA-2082 forms provide a variety of information on Medicaid recipients and payments. For example, information on recipients is provided both by age of recipient and by recipient eligibility status. The data presented here are based on the age of the recipient. Children, as defined by eligibility status, are those children in families with dependent children (whether or not they are receiving cash assistance). Recipient and payment amounts for children based solely on age will always be larger than the amounts for dependent children based on eligibility. Information based on age includes children eligible for Medicaid because of disabilities and other children, such as Ribicoff children.

77/ OBRA86 requires a specified percentage of any appropriations over $478 million to be retained by the Secretary for these purposes. This percentage is 7 percent in FY 1987, 8 percent in FY 1988, and 9 percent in FY 1989.

78/ Primary health services are defined as outpatient assessment, diagnosis, or treatment services designed to promote health, to prevent disease or disability, or treat an illness or other health condition. They may include services to promote access to high quality, continuous, and comprehensive primary health services, including case management.

79/ Community-based service networks for children with special health care needs are defined as networks of coordinated high-quality services that are located in or near children's home communities, in order to improve their health status, functioning, and well-being. Case management services are defined as services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services.

80/ These programs were the maternal and child health services, crippled children's services, Supplemental Security Income benefits for disabled children, lead-based paint poisoning prevention, sudden infant death syndrome, adolescent pregnancy prevention, genetic disease testing and counseling, and hemophilia diagnostic and treatment centers programs.

81/ ERISA exempts Hawaii, allowing that State to continue its law requiring employers to provide health insurance coverage.